Beyond the stereotypes
characterising the unique features of under-researched eating disorder populations, and implications for treatment

Kinnaird, Emma

Awarding institution:
King's College London

Beyond the stereotypes: characterising the unique features of under-researched eating disorder populations, and implications for treatment

Emma Kinnaird

Institute of Psychiatry, Psychology and Neuroscience

King's College London

Thesis submitted for the degree of Doctor of Philosophy (PhD)

2020

Abstract

There are concerns that certain population groups may be underrepresented in the evidence base for eating disorder treatments. This has implications for clinical practice: if eating disorders in these groups are associated with unique features not recognised in previous research, then there is a risk that existing treatment approaches lack applicability in these populations. The aim of the thesis was to explore whether under-recognised minority groups within wider eating disorder populations have unique features that could require treatment adaptations. The thesis focuses on two groups: men with eating disorders, and autistic people with anorexia nervosa.

The first stage of the thesis explored this overall aim through qualitative studies investigating the views of stakeholders across the two groups (Chapters 3-7). The findings indicated that men with eating disorders do not necessarily require fundamentally different treatment approaches compared to their female peers. Rather, stakeholders highlighted the importance of an individualised approach to treatment within an inclusive environment, with gender forming an aspect of this individuality rather than being viewed as a defining feature. By contrast, the qualitative studies indicated that autistic people with anorexia nervosa have specific needs that require treatment adaptations.

The aim of the second stage of the thesis was to further explore these needs in autistic people with anorexia nervosa. The primary focus of this second stage was exploring associations between sensory sensitivity and autistic traits in people with anorexia nervosa (Chapters 10-13). This stage additionally includes a qualitative study exploring eating behaviours in autistic adults (Chapter 8), and a meta-analysis demonstrating a heightened prevalence of alexithymia in autistic people (Chapter 9). The findings suggest that people with anorexia nervosa do not experience objective differences in sensory sensitivity in the areas of taste, smell and interoception, but that further research is required to explore whether sensory sensitivity represents a unique need in autistic people with anorexia nervosa. Finally, stakeholder recommendations that sensory differences need to be recognised and addressed in treatment were implemented in a pilot study exploring the use of a brief sensory screening questionnaire. Overall, the results of the thesis indicate that autistic people with anorexia nervosa may benefit from treatment adaptations, but further empirical research is needed to illuminate the extent to which this group experiences unique needs compared to people with anorexia nervosa only.

Acknowledgements

Firstly, I would like to thank my brilliant supervisors, Prof. Kate Tchanturia and Dr. Catherine Stewart, for everything that you have done for me over the past three years. I consider myself so lucky to have had both of you helping me through this process. Catherine, thank you for your constant support, and for all of your helpful advice and insight. Kate, you have been absolutely wonderful. I feel really privileged to have had the opportunity to work with you and as part of your lab. You have taught me so much and given me so many opportunities. Doing a PhD with you has been an incredible experience and I am so grateful.

I would also like to thank everyone in Kate's lab and on the PEACE pathway for being such lovely people to work and collaborate with. I'd particularly like to thank Caroline Norton and Caroline Pimblett for all of their help and support with my research on the eating disorder unit, and for their invaluable clinical insight. Also to Katie and Yasemin, who have always been so supportive and so kind. I am certain that you will both make brilliant clinical psychologists.

As well as all my co-authors who contributed to this research, I am also very grateful to all of my participants for their time and insight. I hope that you found the experience worthwhile, and that the research that you contributed towards will translate into meaningful treatment improvements for men and autistic people with eating disorders.

I would like to give an honourable mention to the dishonourable rabbits, Matilda and Taggart. Finally, I would like to dedicate this thesis to my parents, and to Phil. My parents have always given me their unconditional support, and made me believe that anything is possible. Whilst that may have been a mistake when I went through that phase of wanting to be an astronaut, knowing that you have always believed in me and that you are always there has given me the confidence to do so many things and pursue what is important to me. I am incredibly grateful. Phil- I would not have made it through this PhD without you. I have leaned on you so many times over the past two years and you have never complained, only shown me love and told me that I can do this. You make everything wonderful. Thank you.

Funding

The candidate was funded by a Medical Research Council Doctoral Training Partnership Studentship (MR/N013700/1).

Abbreviations Used Throughout the Thesis

AASP	Adolescent/Adult Sensory Profile
ADHD	Attention Deficit Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview, Revised
ADOS	Autism Diagnostic Observation Schedule
APA	American Psychiatric Association
AN	Anorexia Nervosa
AN-BP	Anorexia Nervosa: Binge/Purge Subtype
AN-R	Anorexia Nervosa: Restrictive Subtype
AQ	Autism Quotient (Original Version)
AQ-10	Autism Quotient (10 Item Version)
ARFID	Avoidant/Restrictive Food Intake Disorder
ASD	Autism Spectrum Disorder
BED	Binge Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
BPQ	Body Perception Questionnaire
BVAQ	Bermond-Vorst Alexithymia Questionnaire
CAT	Cognitive Analytical Therapy
CBT	Cognitive Behavioural Therapy
CBT-E	Enhanced Cognitive Behavioural Therapy
CI	Confidence Interval
CREST	Cognitive Remediation and Emotion Skills Training
CRT	Cognitive Remediation Therapy

DF	Degrees of Freedom
DSM-4	Diagnostic and Statistical Manual of Mental Disorders, fourth edition
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
ED	Eating Disorder
EDE-Q	Eating Disorder Examination Questionnaire
EDI	Eating Disorder Inventory
FPT	Focal Psychodynamic Therapy
G/ml	Grams per millilitre
HADS	Hospital Anxiety and Depression Scale
HC	Healthy Controls
HAT	High Autistic Traits
HM	Her Majesty's
ICD-10	International Statistical Classification of Diseases and Related Health Problems, tenth edition
IQ	Intelligence Quotient
IQR	Interquartile Range
LAT	Low Autistic Traits
MANTRA	Maudsley Anorexia Nervosa Treatment for Adults
MHR	Mean Heart Rate
N	Number
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NT	Neurotypical
ONS	Office for National Statistics
OSFED	Other Specified Feeding or Eating Disorder

RAADS-R	Ritvo Autism Asperger Diagnostic Scale- Revised
RCT	Randomised Control Trial
S	Seconds
SCID-5	Structured Clinical Interview for DSM-5
SD	Standard Deviation
SLAM	South London and Maudsley NHS Foundation Trust
SMR	Standardised Mortality Ratio
SPQ	Sensory Perception Questionnaire
SSCM	Specialist Supportive Clinical Management
SWEAA	SWedish Eating Assessment for Autism spectrum disorders
TAS-20	Toronto Alexithymia Scale (20 Items)
TAS-26	Toronto Alexithymia Scale (26 Items)
DDF	TAS subscale: Difficulty Describing Feelings
DIF	TAS subscale: Difficulty Identifying Feelings
EOT	TAS subscale: Externally-Orientated Thinking
TAU	Treatment as Usual
UK	United Kingdom

Table of Contents

List of Tables

List of Figures

Due to the low quality of figures in copies of published papers inserted into thesis chapters 6, 7, 9, 10 and 11, higher quality versions of figures from these papers are also included in Appendix F.

List of Appendices

Dissemination of Research

Publications Included in Thesis

Chapter 3: Kinnaird, E. & Norton, C., Tchanturia, K. (2018). Clinicians' views on treatment adaptations for men with eating disorders: a qualitative study. *BMJ Open, 8*. doi:10.1136/bmjopen-2018-021934

Chapter 4: Kinnaird, E., Norton, C., Pimblett, C., Stewart, C. & Tchanturia, K. (2019). "There's nothing there for guys". Do men with eating disorders want treatment adaptations? A qualitative study. *Eating and Weight Disorders, 24*(5), 845-852. doi:10.1007/s40519-019-00770-0

Chapter 5: Kinnaird, E., Norton, C. & Tchanturia, K. (2017). Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study. *BMC Psychiatry, 17*, 292. doi:10.1007/s40519-019-00770-0

Chapter 6: Kinnaird, E., Norton, C., Stewart, C. & Tchanturia, K. (2019). Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment? *International Review of Psychiatry, 31*(4), 308-317. doi:10.1080/09540261.2018.1531831

Chapter 7: Adamson, J. & Kinnaird, E., Glennon, D., Oakley, M., & Tchanturia, K. (2020). Carers' views on autism and eating disorders comorbidity: qualitative study. *BJPsych Open, 6*(3), e51. doi:10.1192/bjo.2020.36

Chapter 8: Kinnaird, E., Norton, C., Pimblett, C., Stewart, C., & Tchanturia, K. (2019). Eating as an autistic adult: An exploratory qualitative study. *PloS One, 14*(8), e0221937. doi:10.1371/journal.pone.0221937

Chapter 9: Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry, (55)*, 80–89. doi:10.1016/j.eurpsy.2018.09.004

Chapter 10: Kinnaird, E., Stewart, C. & Tchanturia, K. (2018). Taste sensitivity in anorexia nervosa: A systematic review. *International Journal of Eating Disorders, 51*(8), 771-784. doi:10.1002/eat.22886

Chapter 11: Kinnaird, E., Stewart, C. & Tchanturia, K. (2020). The relationship of autistic traits to taste and olfactory processing in anorexia nervosa. *Molecular Autism, 11*(25). doi:10.1186/s13229-020-00331-8

Chapter 12: Kinnaird, E., Stewart, C. & Tchanturia, K. (2020). Interoception in Anorexia Nervosa: Exploring Associations With Alexithymia and Autistic Traits. *Frontiers in Psychiatry*. doi:10.3389/fpsyt.2020.00064

Chapter 13: Kinnaird, E., Dandil, Y., Li, Z., Smith, K., Pimblett, C., Agbalaya, R., Stewart, C. & Tchanturia, K. (2020). Pragmatic Sensory Screening in Anorexia Nervosa and Associations with Autistic Traits. *Journal of Clinical Medicine, 9*(4). doi:10.3390/jcm9041182.

Publications Completed During Course of PhD but not Included in Thesis

Carruthers, S. & Kinnaird, E., Rudra, A., Smith, P., Allison, C., Auyeung, B., Chakrabarti, B., Wakabayashi, A., Baron-Cohen, S., Bakolis, I. & Hoekstra, R.A. (2018). A cross-cultural study of autistic traits across India, Japan and the UK. *Molecular Autism, 9*. doi:10.1186/s13229-018-0235-3

Kinnaird, E. & Kimergård, A., Jennings, S., Drummond, C., & Deluca, P. (2019). From pain treatment to opioid dependence: a qualitative study of the environmental influence on codeine use in UK adults. *BMJ Open*, 9(4), e025331. doi:10.1136/bmjopen-2018-025331

Kinnaird, E. & Sedgewick, F., Stewart, C. & Tchanturia, K. (2019). Exploring self-reported eating disorder symptoms in autistic men. *Autism in Adulthood, 1*(4). doi:10.1089/aut.2019.0017

Conference Oral Presentations Associated with Thesis

Kinnaird, E., Norton, C., Stewart, C. & Tchanturia, K. (2018). Comorbid anorexia nervosa and autism: exploring treatment adaptations. Cognitive Remediation Therapy Conference, King's College London, UK.

Kinnaird, E., Stewart, C. & Tchanturia, K. (2019). Exploring treatment adaptations for co-occurring anorexia nervosa and autism spectrum disorders. British Association for Behavioural & Cognitive Psychotherapies Conference, Bath University, UK.

Kinnaird, E., Stewart, C. & Tchanturia, K. (2019). Exploring the association between autistic traits and sensory sensitivity in anorexia nervosa. Medical Research Council Doctoral Training Partnership Conference, King's College London, UK.

Declaration of the Candidate's Role

Chapter 1: All work is the candidate's own. The candidate received minimal feedback and comments from her supervisors, Prof. Kate Tchanturia and Dr. Catherine Stewart.

Chapter 2: All work is the candidate's own. The candidate received minimal feedback and comments from her supervisor Dr. Catherine Stewart.

Chapter 3: The candidate collected the data together with Caroline Norton. The candidate analysed the data, with input from Caroline Norton and Prof. Kate Tchanturia, and prepared the manuscript. The candidate received comments and feedback from co-authors on the manuscript.

Chapter 4: The candidate collected and analysed the data, with input from Prof. Kate Tchanturia. The candidate prepared the manuscript, and received feedback from co-authors on the manuscript.

Chapter 5: The candidate collected the data together with Caroline Norton. The candidate analysed the data, with input from Caroline Norton and Prof. Kate Tchanturia, and prepared the manuscript. The candidate received comments and feedback from co-authors on the manuscript.

Chapter 6: The candidate collected and analysed the data, with input from Prof. Kate Tchanturia. The candidate prepared the manuscript, and received feedback from co-authors on the manuscript.

Chapter 7: The candidate designed the study. James Adamson collected the data. All authors contributed to data analysis. James Adamson and the candidate prepared the manuscript for publication, with feedback from other co-authors.

Chapter 8: The candidate collected and analysed the data, with input from Prof. Kate Tchanturia and Dr. Catherine Stewart on data analysis. The candidate prepared the manuscript, and received feedback from co-authors.

Chapter 9: The candidate conducted the systematic review and meta-analysis, and prepared the manuscript. The candidate received feedback on the manuscript from co-authors.

Chapter 10: The candidate conducted the systematic review and prepared the manuscript. The candidate received feedback on the manuscript from co-authors.

Chapter 11: The candidate collected and analysed the data, and prepared the manuscript. The candidate received feedback on the manuscript from co-authors.

Chapter 12: The candidate collected and analysed the data, and prepared the manuscript. The candidate received feedback on the manuscript from co-authors.

Chapter 13: The candidate collected the data with support from Caroline Pimblett, Yasemin Dandil, Katherine Smith and Rafiu Agbalaya. Following an initial data analysis by Yasemin Dandil and Zhuo Li, the candidate performed the final data analysis and prepared the manuscript. The candidate received feedback on the manuscript from co-authors.

Chapter 14: All work is the candidate's own. The candidate received minimal feedback and comments from her supervisors, Prof. Kate Tchanturia and Dr. Catherine Stewart.

Chapter 1: Introduction

The overall focus of the thesis was on exploring whether under-recognised minority groups within wider eating disorder (ED) populations have unique needs or features that could require treatment adaptations. This chapter begins by introducing EDs and standard treatment approaches used in the United Kingdom (UK), and exploring the concept of health inequality and its implications for treatment provision in the National Health Service (NHS). The thesis focuses on two specific groups identified in previous studies as at risk of experiencing health inequalities that could impact treatment: men with EDs, and autistic people with anorexia nervosa (AN). The literature for each of these groups is reviewed. Finally, the thesis aims are introduced.

1.1 Feeding and Eating Disorders

Feeding and EDs are a group of mental illnesses defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as involving "a persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning" (American Psychiatric Association (APA), 2013). Conditions included in the DSM-5 are AN, bulimia nervosa (BN), binge eating disorder (BED), pica, rumination disorder, and avoidant/restrictive food intake disorder (ARFID). There is additionally a category of "Other Specified Feeding or Eating Disorder" (OSFED), designed for presentations that involve eating disturbances causing impairment or distress, but which do not meet the full criteria for the other conditions.

At present, National Institute for Health and Care Excellence (NICE) treatment guidelines in the UK for EDs only include AN, BN, BED, and OSFED (NICE NG69, 2017). To date, there is no official guidance on treatments for pica, rumination disorder, or ARFID. As this thesis focuses on adapting existing treatment approaches, only conditions included in NICE guidelines will be discussed in detail. Additionally, the thesis will primarily focus on ED treatments in adults.

1.1.1 Anorexia Nervosa

The DSM-5 specifies the following diagnostic criteria for AN (APA, 2013):

- Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.

- Intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.
- Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

AN is divided into two diagnostic subtypes, based on behaviours over the previous 3 months at the point of diagnosis. Restricting type AN (AN-R) is associated with weight loss stemming from dieting, fasting and/or excessive exercise, with no recurrent episodes of binge eating or purging symptoms. Binge-eating/purging type AN (AN-BP) is diagnosed where the individual has experienced recurring episodes of binge eating or purging, such as through self-induced vomiting or laxative abuse. Severity estimates for AN in adults are based on body mass index (BMI). Mild AN is defined where the BMI is ≥ 17. The moderate AN BMI range is 16–16.99, and the severe range is 15–15.99. A BMI < 15 is defined as extreme.

In a review of epidemiological studies in AN using the DSM-5 criteria, lifetime prevalence rates ranged from 0.80% to 3.6%. (Lindvall Dahlgren, Wisting & Ro, 2017). AN most commonly develops when the individual is in adolescence or early adulthood, with evidence that the age of onset may be decreasing in younger generations (Favaro, et al, 2009; Volpe, et al., 2016). Longitudinal research in adults suggests that around 50% of individuals with AN recover, with the remaining half continuing to either fully or partially fulfil diagnostic criteria for AN (Steinhausen, 2009). AN is associated with the highest mortality rates of EDs, with a standardised mortality ratio (SMR) of around 5.86 (Arcelus, Mitchell, Wales & Nielsen, 2011).

1.1.2 Bulimia Nervosa

The DSM-5 specifies the following diagnostic criteria for BN (APA, 2013):

- Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:
    - Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances.
    - A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).

- Recurrent inappropriate compensatory behaviours in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise.
- The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for 3 months.
- Self-evaluation is unduly influenced by body shape and weight.
- The disturbance does not occur exclusively during episodes of AN.

Severity estimates are based on the frequency of inappropriate compensatory behaviours, although these may be adjusted for the presence of other symptoms or degree of functional disability. Mild BN is defined as an average of 1-3 episodes per week, moderate as 4-7, severe as 8-13, and extreme as 13 or more episodes.

Only a small number of studies have assessed lifetime prevalence for BN using DSM-5 criteria, with estimates ranging from 0.28% to 2.6% (Stice, Marti & Rohde, 2013; Udo & Grilo, 2018). Similarly to AN, individuals typically develop BN in adolescence or early adulthood, with age of onset decreasing in younger generations (Favaro, et al., 2009). Approximately 50% of people with BN fully recover, with the remaining 50% either continuing to meet full criteria, or continuing to experience some level of symptomatology (Keek & Mitchell, 1997). BN is associated with a heightened mortality rate compared to the general population, with an SMR of around 1.93 (Arcelus, et al., 2011).

1.1.3 Binge Eating Disorder

BED was included as an ED for the first time in the most recent edition of the DSM, with the following diagnostic criteria (APA, 2013):

- Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:
    - Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most people would eat in a similar period of time under similar circumstances.
    - A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).
- The binge-eating episodes are associated with three (or more) of the following:
    - Eating much more rapidly than normal.

    - Eating until feeling uncomfortably full.
    - Eating large amounts of food when not feeling physically hungry.
    - Eating alone because of feeling embarrassed by how much one is eating.
    - Feeling disgusted with oneself, depressed, or very guilty afterward.
- Marked distress regarding binge eating is present.
- The binge eating occurs, on average, at least once a week for 3 months.
- The binge eating is not associated with the recurrent use of inappropriate compensatory behaviour as in BN and does not occur exclusively during the course of BN or AN.

BED severity is judged based on the frequency of binge eating episodes, although may be adjusted to reflect the presence of other symptoms and the degree of functional disability. Mild BED is defined as 1-3 episodes per week, moderate as 4-7 episodes, severe as 8-13 episodes, and extreme as 14 or more episodes.

BED is thought to be more common compared to AN and BN, with lifetime prevalence estimates ranging from 2.1 to 3.6% (Lindvall Dahlgren, Wisting & Ro, 2017). Whilst the relatively new status of BED in the literature means that there is less research on outcomes, a longitudinal community study found that the majority of people experiencing binge eating recovered, with only 10% of participants meeting full criteria after 5 years (Fairburn, et al., 2000). Although there is a lack of research on BED and mortality outcomes, individuals with BED could be at greater risk of negative health outcomes due to associations with higher weight and obesity (de Zwaan, 2001).

1.2 Eating Disorder Treatment

In the UK, the recommended provision of ED treatments through the NHS is informed by the NICE guidelines. These provide a framework of treatment recommendations for AN, BN and BED, with the guidelines for OSFED suggesting that individuals should be treated for the ED their condition most closely resembles (NICE NG69, 2017). For all conditions, NICE recommends that medication should only be offered together with psychological interventions, and never as the sole treatment.

1.2.1 Anorexia Nervosa

In the UK, NICE guidelines recommend one of three individual psychological treatments for adults with AN: enhanced cognitive behavioural therapy (CBT-E), Maudsley Anorexia Nervosa Treatment for Adults (MANTRA), and Specialist Supportive Clinical Management (SSCM).

CBT-E is a transdiagnostic therapy designed for use across the EDs (Fairburn, Cooper & Shafran, 2003). CBT-E is based in a cognitive-behavioural model which views EDs as driven by key maintaining processes of the over-evaluation of shape, weight and eating and their control; perfectionism, low self-esteem, mood intolerance, and interpersonal difficulties. CBT-E includes aspects of psychoeducation, formulation, behavioural monitoring and experiments, cognitive strategies, and relapse prevention (Fairburn, 2008).

MANTRA is based on the cognitive-interpersonal maintenance model of AN, which suggests that AN is maintained through rigid and detail-focused thinking styles, poor emotional recognition and emotional avoidance, beliefs about the positive utility of AN for the individual, and through the responses of close others (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Unlike CBT-E, MANTRA does not focus on weight and shape concerns. The treatment includes aspects of emotion skills training, cognitive remediation therapy, and motivational interviewing.

SSCM is not based on a specific model, but instead aims to promote normal eating and weight restoration through a supportive therapeutic relationship, goal-setting, physical monitoring, psychoeducation and nutritional advice (McIntosh, et al., 2006).

Additionally, ED-focused focal psychodynamic therapy (FPT) is recommended where these treatments are ineffective or unacceptable (Zipfel, et al., 2014). This approach uses psychodynamic techniques to explore the individual's interpersonal relationships, and the link to their ED symptoms.

In a systematic review and meta-analysis of randomised control trials (RCTs) accompanying the treatment guidelines for AN, the quality of evidence in these studies was determined to be low to very low. This reflects findings from other reviews highlighting that although psychological treatments for AN appear to be beneficial over treatment as usual (TAU), the evidence remains uneven and limited (Hay, Touyz, & Sud, 2012; Watson & Bulik, 2013). In this context, at present no first line treatment for AN is recommended by NICE guidelines in the UK.

As well as psychological interventions, weight restoration in AN is considered a key goal, and the individual may be offered dietary counselling.

1.2.2 Bulimia Nervosa

NICE guidelines recommend that adults experiencing BN are initially offered supervised self-help programmes as a first line treatment, supplemented with brief supported sessions. Self-help programmes for this population are typically based in CBT principles (Sysko & Walsh, 2008). If ineffective, unacceptable or contraindicated, individual CBT-E is recommended as a second line treatment.

1.2.3 Binge Eating Disorder

Similarly to BN, NICE guidelines indicate that adults with BED should first be offered self-help treatments. These approaches typically have a CBT basis (Sysko & Walsh, 2008). Where ineffective, NICE recommends the individual is first offered a group-based CBT-E intervention, with individual CBT-E only provided if a group programme is unavailable, or declined by the patient.

1.2.4 Treatment Setting

ED treatments are typically first offered on an outpatient basis. However, where physical health is severely compromised and medical stabilisation is required, such as in severe AN, individuals may be offered inpatient or day patient care. NICE guidelines specify that these decisions should be made on the basis of physical health risks: for individuals who present a high mental health risk (such as suicidality), psychiatric inpatient care facilities may be more appropriate. ED inpatient services typically focus on medical stabilisation, although the guidelines recommend that psychological treatments are started or continued. These psychological treatments may be delivered on an individual or group basis. Examples of group treatments offered in inpatient services include body image work (Key, et al., 2002), emotion skills training (Adamson, Leppanen, Murin & Tchanturia, 2018), and cognitive remediation therapy (CRT; Tchanturia, Larsson & Brown, 2016).

1.3 Health Inequality

Individuals access and respond to ED treatment differently. One individual might quickly recognise and seek help for their ED symptoms whilst another might not ever pursue or receive treatment (Ali, et al., 2016). People may or may not complete treatment, they may or may not experience a reduction in their symptoms, and different people can have very different treatment experiences. This variation in outcomes is sometimes partly attributable to individual clinical features, such as BMI, motivation to recover, depression, or family problems (Vall & Wade, 2015). However, sometimes this variation is not solely due to clinical predictors, and clear disparities in treatment experiences and outcomes are observed across different population groups. In the ED field, a growing body of evidence suggests that unmet treatment needs are disproportionately experienced by groups who do not conform to traditional stereotypes of EDs as affecting “skinny, white, affluent girls” (Sonneville & Lipson, 2018).

The issue of disparities in treatment falls under the wider concept of health inequality, a broad term which refers to differences in the health of individuals and groups (Kawachi, Subramanian & Almeida-Filho, 2002). Health inequalities are most commonly conceptualised at a social group level (Arcaya, Arcaya & Subramanian, 2015). Some social groups are based on defined and commonly

accepted membership categories, such as gender, race or religion. Others are based on more fluid and continuous qualities, such as income level. These groups can co-occur and interact in their production of health outcomes: for example, some ethnic minority groups may be more likely to also have lower incomes (Adler & Rehkopf, 2008).

Health inequalities between groups can be driven by multiple, often interacting factors. Arcaya and co-authors (2015) distinguish between four categories of explanations for health inequalities:

- Material factors. These can include access to resources, or physical risk factors such as pollution. Access to effective and group-appropriate treatments would fall under this category.
- Psychosocial factors. This reflects the extent to which certain social groups are more likely to experience stressful or negative emotional events, such as social exclusion or discrimination.
- Behavioural differences. Different groups may be more or less likely to engage in health-related behaviours, whether positive (e.g. accessing cancer screening services) or negative (e.g. smoking prevalence rates). These differences may be related to material factors, for example not accessing healthcare may reflect a lack of appropriate service provision.
- Biomedical factors. These reflect potential biological risk factors that may be specific to certain groups.

The presence of enduring health inequalities across groups raises issues of unfairness and injustice, particularly where they are based in inequalities of opportunity, access or discrimination (Woodward & Kawachi, 2000). Health inequalities also result in financial costs: in the UK, poorer health related to lower socio-economic status is estimated to cost the NHS £4.8 billion per year (Asaria, Doran & Cookson, 2016). In this context, the UK has introduced legislation mandating NHS England to work to reduce health inequalities (Health and Social Care Act, 2012). This includes a legal duty to "have regard to the need to reduce inequalities between patients in access to health services and the outcomes achieved". In practice, this involves identifying groups that may experience inequalities in access to treatment and/or treatment outcomes, and taking action to reduce these inequalities (NHS England, 2015). The Act does not specify a list of groups, but instead covers any group potentially experiencing health inequalities.

The current thesis will focus on potential inequalities in ED treatment service provision for two groups: men, and autistic people. These groups are thought to represent a minority (albeit potentially significant minority) of people with EDs, and are under-represented in existing research on ED treatment. Therefore, current treatments for EDs reflect a research base that has not always

included or addressed the needs of these groups. With evidence that these populations might be at risk of experiencing health inequalities in this field, there is a need for research on whether treatments require adaptations for these groups to ensure equitable experiences and outcomes.

1.4 Men with Eating Disorders

Historically, EDs have been viewed as a primarily female illness (Till, 2011). The majority of people diagnosed with EDs are women (see below for a full discussion of sex prevalence), and this has created a circularity in the field: the majority of people with an ED are women, therefore the majority of research, including clinical treatment trials, are performed on women (Murray, Nagata, et al., 2017; Striegel, Bedrosian, Wang & Schwartz, 2011). Consequently, EDs have historically been classified, assessed and treated as a specifically female illness, risking the exclusion of men and so reinforcing the original sex skew (Mitchison & Mond, 2015). For example, the previous DSM-4 definition of AN included amenorrhea as a compulsory criterion for a full diagnosis, with no recognition that this would not apply to men (APA, 2000). Moreover, the historical focus on body image disturbances as rooted in a drive for thinness has been driven by research with female participants, whereas more recent research has recognised that men may in fact be motivated by a lean muscular body ideal (Murray, Griffiths & Mond, 2016).

Therefore, men with EDs have long been "under-diagnosed, undertreated, and misunderstood" (Strother, Lemberg, Stanford & Turbeville, 2012). However, there is a growing research interest in male EDs, with implications for how health services can ensure treatment equality in this population.

1.4.1 Prevalence

The often-cited figure for how many men experience EDs compared to women is that 1 in 10 people with an ED is a man (Gotestam, Eriksen, Heggestad, & Nielsen, 1998; Striegel-Moore, Lesile, Petrill, Garvin, & Rosenheck, 2000). However, there is an increasing awareness that men may represent a greater proportion of the ED population than previously thought, with more recent estimates putting the figure closer to around 1 in 4 (Hudson, Hiripi, Pope, & Kessler, 2007; Kjelsas, Bjornstrom, & Gotestam, 2004; Sweeting, et al., 2015).

There is also variation across the different EDs, and across clinical and community samples. The male:female sex ratio for AN appears to be around 1:4 in community samples (Hudson, et al., 2007), and around 1:10 in clinical samples (Striegel-Moore, et al., 2000). For BN, the ratio has been estimated at 1:4 in community samples (Hudson, et al., 2007; Kjelsas, et al., 2004), with clinical estimates ranging widely from 1:20 to 1:10 (Button, Aldridge & Palmer, 2008; Micali, Hagberg, Petersen & Treasure, 2013). At present there is a lack of research on sex prevalence in clinical binge

eating samples; however, community samples suggest that the sex ratio for BED may be less skewed at around 1:3 (Hudson, et al., 2007; Kjelsas, et al., 2004). Although clinical data is not available, one study did find that men with BED were less likely to seek treatment compared to women (Kessler, et al., 2014). Finally, there is evidence that ED gender ratios are more balanced in other feeding and eating conditions. For example, studies suggest that boys could account for around 50% of ARFID cases in children and adolescents (Bryant-Waugh, 2019; Cooney, et al., 2018; Eddy, et al., 2015; Nicely, et al., 2014).

Therefore, it is evident that men form a higher proportion of the ED population than previously thought, albeit still a minority compared to women. Although there is a common perception in the media that EDs are increasing in men, research studies in this area are more inconsistent (Sweeting, et al., 2015). Whilst there is some evidence that disordered eating behaviours are increasing in men, the prevalence of diagnosed EDs in men has remained constant over the past decade (Jaworski, et al., 2019; Mitchison, Hay, Slewa-Younan & Mond, 2014). This discrepancy between disordered eating and diagnosed EDs could reflect that men may be less likely to meet diagnostic criteria (Mitchison & Mond, 2015). For example, the male:female sex ratio in individuals who meet "full" criteria for AN is 1:5, but the proportion of men rises to around 1:3 in people who meet "partial" criteria (Woodside, et al., 2001).

1.4.2 Research Representation

Men have traditionally been under-represented in ED research (Murray, Nagata, et al., 2017; Striegel, et al., 2011). Therefore, there is a risk that existing conceptualisations and related treatments for EDs are based in research that may not reflect the needs of male patients. This concern is exemplified by the evidence for ED treatments in the UK. The provision of ED treatments in the UK is based on the NICE guidelines, with the most recent edition issued in 2017. The guidelines are based on a series of systematic reviews and meta-analyses in relevant areas (for example, reviewing the evidence for individual psychological interventions in EDs) that assess the existing literature. These are then used to create evidence-based recommendations for clinical practice. In the development of the most recent guidelines, authors meta-analysed the findings of RCTs of psychological interventions for EDs (NICE NG69, 2017). These studies are summarised in Table 1, located at the end of this chapter. Five studies did not report participant sex and so are not included in this overview. The samples from follow-up studies on the original RCTs are also not included. Therefore, the following characteristics were calculated from a total of 22 RCTs in AN, 43 RCTs in BN, and 32 RCTs in BED.

Where participant sex was reported, on average men represented just 4.10% of the participants in studies on AN, with 45.45% (*n*=10) of studies including only women. Men represented 1.37% of the participants in studies on BN, with 67.44% (*n*=29) of studies including only women. Finally, men represented 8.03% of the participants in studies on BED, with 46.88% (*n*=15) of studies including only women. Men are under-represented in ED treatment trials, even compared to conservative and potentially outdated estimates that men represent 1 in 10 people with EDs (Gotestam, et al., 1998; Striegel-Moore, et al., 2000). Therefore, there is a risk that existing treatment recommendations in the UK may not fully capture or meet male-specific needs.

1.4.3 Presentation

Do men with EDs have specific needs compared to women? There appear to be more similarities than differences in how EDs present across men and women, although this may reflect the fact that "female-centric" diagnostic criteria could exclude men with atypical presentations (Bramon-Bosch, Troop & Treasure, 2000; Mitchison & Mond, 2015; Nunez-Navarro, et al, 2012; Perko, et al., 2019). However, a number of potential sex differences have been identified. ED onset and diagnosis in men may occur at an older age compared to women (Machado, et al., 2020; Carlat, Camargo & Herzog, 1997). Men with AN may also have higher BMIs compared to women, and are more likely to present with a history of being overweight (Gueguen, et al., 2012; Welch, Ghaderi & Swenne, 2015). This could suggest that men with EDs experience greater weight fluctuations (Machado, et al., 2020). Although men accessing treatment do not appear to differ compared to women in the frequency of their ED behaviours, there is some evidence that they experience lower levels of related psychopathology including anxiety, body image concern, and obsessive-compulsive traits (Gueguen, et al., 2012; Nunez-Navarro, et al., 2012). However, men with EDs appear to be more likely to engage in compulsive exercise, and are more likely to experience excessive exercise prior to illness onset (Machado, et al., 2020; Murray, Griffiths, Rieger & Touyz, 2014). Additionally, despite lower levels of anxiety and obsessive-compulsive features, men with EDs are at higher risk of experiencing other diagnosed comorbid psychiatric conditions, particularly substance use and mood disorders (Bramon-Bosch, et al., 2000; Striegel-Moore, Garvin, Dohm & Rosenheck, 1999). Homosexuality also appears to be a specific risk factor for ED symptoms in men, with homosexuality and bisexuality more common in men with EDs compared to women (Boisvert & Harrell, 2009; Bramon-Bosch, et al., 2000; Carlat, et al., 1997). This may be related to heightened media and peer pressures surrounding body image in this population (Morgan & Arcelus, 2009).

A significant amount of research interest in sex differences in ED presentation has focused on the potential impact of masculine gender roles, particularly in relation to body image concerns. Gender

roles refer to behaviours and attitudes prescribed by society as appropriate to the male or female gender (Connell, 1995). In Western society, traditionally male behaviours and attitudes include confidence, dominance, strength, and self-control (Connell, 1995). A related socio-cultural pressure is that of the ideal male body, with men typically desiring a bigger, muscular body with low body fat (Cohane & Pope, 2001). Men who endorse traditionally masculine gender roles appear to be more likely to have body image concerns surrounding muscularity, whereas feminine role endorsement is associated with the pursuit of thin body ideals (Murray, Rieger, Karlov & Touyz, 2013).

There is some evidence that cultural male body image ideals may offer men a degree of protection from disordered eating in the general population, as they appear to be closely aligned with concepts of biological health, physical fitness and prowess (Mickalide, 1990, Morgan & Arcelus, 2009). For example, one study found that men without EDs were more likely to endorse a classically masculine "muscular, strong, and broad shoulders" body image ideal, in contrast to men with EDs who described a lean, thin shape. (Kearney-Cooke & Steichen-Asch, 1990). However, research suggests that muscularity-focused body image concerns could impact eating behaviours in men in ways that have not been traditionally accounted for in ED conceptualisation and assessment, which may result in under-diagnosis (Griffiths, Murray & Touyz, 2013; Murray, et al., 2018). Men with AN may be less concerned with weight loss or thinness, and so present with low scores on traditional diagnostic measures which assess weight and shape concern (Darcy, et al., 2011; Strober, et al., 2006). There is also increasing research interest in whether the dietary phenomenon of men following a restrictive low calorie/high protein diet in pursuit of a muscular lean body, interspersed with planned high calorie "cheat meals", resembles cycles of binging and restriction in BN (Pila, et al., 2017). In addition, men presenting with muscle-orientated disordered eating are more likely to use muscle-enhancing drugs compared to those with AN (Murray, Rieger, Hildebrandt, et al., 2012). This has led to proposals that current ED classifications need to better acknowledge the potential role of muscle-focused disordered eating (Murray, Rieger, Touyz & De la Garza Garcia, 2010).

Finally, an additional aspect of male ED presentations related to societal gender roles are feelings of shame and/or emasculation related to experiencing a "female" illness (Lyons, McAndrew & Warne, 2019; Raisanen & Hunt, 2014). Research suggests that men may be more likely to have negative perceptions around people with EDs compared to women, in particular perceiving individuals with EDs as less masculine (Griffiths, Mond, Murray & Touyz, 2014). Significantly, not all men endorse societal masculine gender norms in the same way, and so individual men may be more or less impacted by these kinds of social pressures. For example, men with higher conformity to masculine gender norms are more likely to have negative perceptions of EDs, and so may be more vulnerable to self-stigmatisation (Austen & Griffiths, 2018).

1.4.4 Risk of Health Inequalities

Men and women are known to experience different health outcomes. For example, men have lower life expectancies: the most recent UK figures estimate life expectancy at birth as 79.3 years for men, and 82.9 years for women (Office for National Statistics (ONS), 2019a). However, men spend a greater proportion of their lives free from disabilities compared to women (79.5% compared to 76.0%, ONS, 2016). There is also evidence for gender disparities in mental health. Mental health problems are more common in women, with 1 in 5 women in the UK meeting criteria for a common mental health problem compared to 1 in 8 men (McManus, et al., 2016). The same report found that women are more likely than men to experience self-harm, suicidal thoughts, and suicide attempts. However, 75.45% of registered deaths by suicide in the UK are among men (ONS, 2019b). Men have more negative attitudes surrounding seeking psychological help compared to women, and less likely than women to receive any form of psychological treatment (McManus, et al., 2016; Nam, et al., 2010).

Lower help-seeking for mental health problems in men appears to be closely related to pressures surrounding masculine cultural roles, with conformity to masculine norms associated with lower help-seeking and poorer mental health outcomes in both men and women (Wong, et al., 2017). The process of help-seeking may conflict with internalised expectations around masculinity, particularly a need to avoid the appearance of weakness or emotionality (Rasmussen, Hjelmeland & Dieserud, 2018; Rice, et al., 2018; Seidler, et al., 2016). There may also be concerns about judgements from male family members or peers. Consequently, men are at risk of adapting maladaptive coping styles in place of help-seeking, including substance abuse and risk-taking behaviours (Seidler, et al., 2016). However, evidence does suggest that men may be more likely to seek help and engage with mental health treatment if tailored services are provided (Sagar-Ouriaghli, et al., 2019; Seidler, et al., 2016). Potential adaptations include reframing traditional masculine norms into models of positive masculinity, providing male-sensitive materials, and psychoeducation. There is also some evidence that men may respond more to an action-orientated, problem-solving therapeutic approach (Emslie, et al., 2007; Syzdek, et al., 2016).

In the context of this wider mental health research, understanding health inequalities in male experiences of ED services is particularly important as these difficulties may be exacerbated by ED-specific factors. In particular, the conflict between help-seeking and masculinity may be particularly heightened with EDs commonly perceived as a feminine illness. As highlighted in the “Prevalence” section, the estimated proportion of men in ED populations tends to be lower in clinical samples, but higher in community samples (Sweeting, et al., 2015). Men with EDs are less likely than their female

peers to perceive a need for treatment, to receive a diagnosis, or to receive treatment (Hay, Loukas & Philpott, 2005; Sonneville & Lipson, 2018; Thapliyal, Mitchison, Miller, et al., 2017). One possibility is that the popular perception of EDs as a female illness means that men do not recognise their symptoms as EDs (Dearden & Mulgrew, 2013; Lyons, et al., 2019; Raisanen & Hunt, 2014). However, a recent study found that men are no less likely than women to recognise their ED symptoms, suggesting additional factors may make men less likely to pursue diagnosis and treatment (Grillot & Keel, 2018). One potential factor could be stigma around help-seeking (Griffiths, Mond, et al., 2015). Peers and family members may also be less likely to recognise that men are experiencing EDs and so encourage them to pursue help (Arnow, et al., 2017). When men do seek help stereotypes surrounding EDs may also impact the decision making of clinicians themselves, with evidence suggesting that primary care healthcare professionals are less likely to diagnose men with an ED and refer to specialist treatment services (MacCaughelty, Wagner & Rufino, 2016; Raisanen & Hunt, 2014).

Recent changes in UK health legislation may also act as a barrier to men accessing appropriate ED treatment. In 2010, the UK Department of Health issued guidelines eliminating mixed-sex accommodation in NHS services (NHS England & NHS Improvement, 2019). NHS services are required to provide same-sex sleeping and bathroom spaces, and mental health inpatient units must also provide a same-sex day space. Units not complying with this guidance can receive financial sanctions. This has raised concerns in the ED field: as men form an (albeit significant) minority of ED patients, ED inpatient units may not have resources to provide separate same-sex accommodation. Therefore, there is a risk that men could struggle to access inpatient treatment. These concerns are reflected in a recent service evaluation study of inpatient ED units in the UK: out of 26 units that responded to the study, 6 did not admit men, and 3 of those units stopped admitting men following the new guidelines (Fukutomi, et al., 2018).

1.4.5 Implications for Treatment

Therefore, it is evident that men with EDs experience a number of barriers to seeking treatment. Once men with EDs do access treatment, it is less clear whether their treatment experiences are altered or disadvantaged due to their gender. A systematic review of research on sex differences in AN treatment outcome found no significant differences between men and women (Strobel, et al., 2018). One study has found that men with diagnoses of BN or OFSED who complete treatment may in fact have better outcomes due to their female counterparts, but that men were more likely to drop-out of treatment prior to completion (Aguera, et al., 2017).

Whilst the impact of sex on measurable treatment outcomes varies across studies, qualitative and survey studies do suggest that being a man can potentially impact service experiences. Difficulties include being a minority in female-dominated treatment groups or settings, a lack of resources or facilities for men, and experiencing different issues to women (for example, differing cultural pressures around body image) that may not be fully addressed in treatment (Lyons, et al., 2019; Morgan, Key & Lacey, 1998; Robinson, Mountford & Sperlinger, 2012). However, there also appears to be a lack of consensus around how central sex is to treatment experiences, with participants within studies disagreeing on whether they felt they had male-specific issues that needed to be addressed in treatment, or if they perceived themselves as similar to their female peers (Dearden & Mulgrew, 2012; Robinson, et al., 2012; Thapliyal & Hay, 2014).

Therefore, whilst potential inequalities in male ED service experiences have been identified, it is unclear how these can be practically addressed. There is disagreement around whether men could benefit from adapted treatment approaches, or if men should receive similar treatments as women (Dearden & Mulgrew, 2012; Robinson, et al., 2012; Thapliyal & Hay, 2014). Furthermore, what kinds of adaptations could benefit male patients is also unclear. Potential changes to standard interventions include body image work that recognises male-specific body concerns, exploring concepts of masculinity, and adapting a problem-solving approach in treatment (Andersen, 1990; Kearney-Cooke & Steichen-Asch, 1990; Morgan, 2008). There is also disagreement about what kind of treatment settings are most appropriate for this population. Some studies have proposed that men could benefit from all-male treatment environments to combat the perception of EDs as a female illness, including all-male treatment groups and male clinicians (Dearden & Mulgrew, 2012; Weltzin, et al., 2012). However, these suggestions are based on the opinions and experiences of service providers and clinicians, and the views of male patients themselves on sex-specific treatment appear to be mixed (Dearden & Mulgrew, 2012; Robinson, et al., 2012; Thapliyal & Hay, 2014).

A second possibility is the provision of male-friendly, but otherwise integrated treatment pathways. This approach was piloted in a recent study which provided a male-specific assessment and treatment track integrated in its wider service: men were provided with standard individual CBT sessions and accessed the service's wider mixed-sex group sessions, but also provided with additional support around male-specific issues including normalising male EDs and addressing related stigma (MacNeil, Hudson & Leung, 2018). Following the implementation of this pathway, the service received significantly more referrals for male patients, and men were more likely to engage in treatment. This reflects wider research in the area of male mental health suggesting that men may be more likely to access treatment services tailored to their needs. (Sagar-Ouriaghli, et al., 2019; Seidler, et al., 2016). However, this study lacks feedback from the male patients themselves on the

benefits or drawbacks of this style of adaptation, and there is a lack of consensus in the literature on what form a tailored treatment service for men would take.

Therefore, research suggests that men are at risk of experiencing health inequalities in ED services. However, the current literature is unclear on whether men require ED treatment adaptations, and exactly what these adaptations might involve. In particular, this area could benefit from greater insight into the views of male patients themselves.

1.5 Autistic People with Anorexia Nervosa

Co-occurring conditions are common in AN, with around 60% of people with AN presenting with at least one psychiatric comorbidity (Jaite, et al., 2013). Previous research on AN and common comorbidities, including implications for treatment and its outcomes, have predominantly focused on comorbid psychopathologies such as depression, obsessive-compulsive disorder, anxiety, and personality disorders (Keshishian, et al., 2019; O'Brien & Vincent, 2003). These are mental health conditions which can also be targeted for treatment alongside the ED, making these comorbidities qualitatively different to autism. Autism is a neurodevelopmental condition that affects people across the lifespan, rather than a mental health condition which can be treated and cured. Autistic people accessing health services are known to experience unique needs associated with their autism which require adapted care (Lake, Perry & Lunsky, 2014). However, despite evidence suggesting autism prevalence may be heightened in people with AN compared to the general population, implications of this comorbidity for the treatment of AN remain an under-explored area (Westwood & Tchanturia, 2017).

1.5.1 Autism

Autism is a neurodevelopmental condition characterised by social communication difficulties, and restricted, repetitive patterns of behaviour (APA, 2013). As autism is a neurodevelopmental condition, onset will always be in the developmental period, although actual diagnosis may be delayed. The DSM-5 specifies the following diagnostic criteria:

- Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history (examples are illustrative, not exhaustive):
    - Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

- Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

- Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):
  - Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  - Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
  - Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  - Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism

spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

- Judgements of severity are based on social communication impairments and restricted, repetitive patterns of behaviour.

Crucially, in contrast to mental health conditions, autism itself cannot be cured. Instead of recovery, there is instead a focus on addressing difficulties or disabilities where they occur, recognising the role of the environment in these difficulties, and an emphasis on adapting around core autistic traits rather than change (Milton, 2014). Consequently, adapting the treatment of co-occurring autism and AN requires a very different approach compared to other comorbidities.

It should be noted that the DSM criteria reflects more traditional models of autism, conceiving autism as a disorder with associated deficits and difficulties. However, autism is increasingly perceived as a condition associated with differences, rather than as a disorder (Fletcher-Watson & Happe, 2019). This reframing has been influenced by the concept of neurodiversity, which views neurological differences as representing natural human variation (Baron-Cohen, 2017; Nicolaidis, 2012; Pellicano & Stears, 2011). Using a neurodiversity approach, autism can be understood as a neurodevelopmental condition in which individuals experience differences which should be valued. These differences can take the form of difficulties (such as with communication) but also strengths (such as attention to detail). Whether these differences act as strengths or difficulties is partially mediated by the environment: these difficulties can become disabling when the individual lives in a society which does not accommodate the needs of autistic people (den Houting, 2018). In light of this evolving approach to understandings of autism, there is also increasing discussion around how to describe individuals with an autism diagnosis. Standard style guides and conventions around language use have previously specified that these individuals should be described using person-first language ("person with autism"), foregrounding the individual before their condition (APA, 2010). This approach is centred around the position that an individual is not defined by their condition, and that linguistically focusing on someone's autism diagnosis is objectifying and reductionist (Dunn & Andrews, 2015). However, the argument that autism should be viewed as a diversity, rather than a disorder, has led to challenges of person-first conventions. Reflecting similar movements in other communities, notably the deaf community, research suggests that adults with an autism diagnosis prefer identity-first language ("autistic person"; Kenny, et al., 2016). Using the term "autistic person" expresses the perspective that autism can be a positive and important part of someone's identity. Consequently, style guides and autism journals increasingly recommend that researchers should use

the terminology favoured by the group under discussion (APA, 2020; Vivanti, 2019). This thesis will use identity-first language when discussing autism: this approach is favoured by autistic adults, and autistic participants self-identified using this language during the thesis interview studies (Kenny, et al., 2016).

In the UK, NICE guidelines recommend a team-based multi-stage process undertaken by trained professionals for the diagnosis of autism in adults (NICE CG142, 2016). For adults presenting with potential autistic traits, and no moderate or severe learning disability, the 10 item Autism Quotient (AQ-10) is recommended as a screening tool prior to a full assessment (Allison, Auyeung & Baron Cohen, 2012). If the individual scores above threshold on the AQ-10, the following areas are evaluated in a comprehensive assessment:

- Core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood.
- Early developmental history, where possible.
- Behavioural problems.
- Functioning at home, in education or in employment.
- Past and current physical and mental disorders.
- Other neurodevelopmental conditions.
- Hyper- and/or hypo-sensory sensitivities and attention to detail.

For individuals without a learning disability, NICE recommends using formal assessment tools such as the Autism Diagnostic Observation Schedule (ADOS), the Autism Diagnostic Interview-Revised (ADI-R), and the Ritvo Autism Asperger Diagnostic Scale- Revised (RAADS-R) (Lord, et al., 1994; Lord, et al., 2000; Ritvo, et al., 2011).

Using a combination of the AQ as a screening tool and the ADOS, the prevalence rate of autism in adults in the UK is estimated at 0.8% with higher rates in men (1.5%) compared to women (0.2%) (McManus, Bebbington, Jenkins & Brugha, 2016). Whilst autism incidence rates in the UK increased significantly during the 1990s, incidence and prevalence rates appear to have remained steady since the early 2000s (Taylor, Jick & MacLaughlin, 2013). Moreover, this increase in prevalence appears to be largely due to changes in diagnostic criteria and data reporting practices (Hansen, Schendel & Parner, 2015).

However, there are growing concerns that autism in women may be underdiagnosed (Lai & Baron-Cohen, 2015). A meta-analysis of estimates suggests that the male:female ratio in autism is around 3:1 (Loomes, Hull & Mandy, 2017). Significantly, the male:female ratio appears to be lower in studies that utilise population screening for autism, and higher in studies that examine people with a pre-existing autism diagnosis. This suggests that women may be less likely to receive a diagnosis, despite meeting criteria. Consequently, the autism field appears to have a similar difficulty to the ED field, but in the opposite direction: the majority of autistic people are thought to be men, but there are concerns that this both reflects and perpetuates the under-diagnosis of women (Hull & Mandy, 2017). Autistic men and women may present differently, with a specifically "female phenotype" of autism not recognised by current diagnostic criteria and assessment tools based in research on predominantly male samples (Kreiser & White, 2014). For example, using current assessment tools autistic girls have equivalent social and communication difficulties to boys, but fewer restricted and repetitive behaviours and interests (Mandy, et al., 2012). There is also evidence that autistic women may develop compensatory or camouflaging behaviours that circumvent or mask their autistic traits (Hull, et al., 2017; Livingston & Happe, 2017). This can result in autism going unrecognised until the costs of these compensatory or camouflaging behaviours become too great, resulting in clinical attention as a result of associated mental health difficulties (Hull, et al., 2017; Livingston, Shah & Happe, 2019; Tierney, Burns & Kilbey, 2016). Finally, co-occurring mental health diagnoses such as anxiety or AN may themselves conceal underlying autism in women (Hull & Mandy, 2017).

1.5.2 Prevalence

A potential link between autism and AN in women was first identified in the early 1980s, with the suggestion that AN and autism could be rooted in common biomedical factors which result in AN in women, and autism in men (Gillberg, 1983). Whilst this theory is no longer endorsed, there do appear to be a number of shared features in autism and AN. People with AN exhibit similar cognitive profiles as seen in autistic people, including difficulties with executive functioning, central coherence, and social cognition, and show comparable levels of repetitive, stereotyped, and compulsive behaviours (Lang, Roberts, et al., 2016; Leppanen, Sedgewick, Treasure & Tchanturia, 2018; Oldershaw, Treasure, et al., 2011; Pooni, et al., 2012; Westwood, Stahl, Mandy & Tchanturia, 2016). People with AN also experience difficulties in social and emotional functioning (Harrison, Sullivan, Tchanturia & Treasure, 2009; Lang, Larsson, et al., 2016; Westwood, Lawrence, Fleming & Tchanturia, 2016).

Research has established that there does appear to be a heightened prevalence of autism in AN populations (Huke, et al., 2013; Westwood & Tchanturia, 2017). Whilst exact estimates vary

depending on the methods used, studies using gold-standard diagnostic assessment measures suggest that around 10-50% of adolescent and adult women with AN present with clinically significant levels of autistic traits (Postorino, et al., 2017; Vagni, et al., 2016; Westwood, Mandy & Tchanturia, 2017a; Westwood, Mandy, Simic & Tchanturia, 2017). Significantly, these cases of co-occurring autism and AN are typically suspected by clinicians, but not formally diagnosed prior to research assessments (Mandy & Tchanturia, 2015). This likely reflects the wider under-diagnosis of autism in women, and reflects concerns that many autistic women do not receive a diagnosis until a decline in their mental health brings them into contact with clinical services (Tierney, et al., 2016). That autistic women may first come into contact with clinical services for mental health treatment, rather than referral to autism diagnostic services, may in itself present an additional barrier to diagnosis. In the UK, the structuring of mental health provision means that different services typically treat different specialisms. ED services are primarily designed to treat people with EDs, whilst a separate autism service or team will diagnose and support autistic people. This silo approach means that non-specialist autism teams may not have the training, supervision or commission to recognise or diagnose autistic people. Therefore, this could contribute to additional barriers and delays for undiagnosed autistic women entering clinical services in the context of a mental health crisis.

Only one study to date has combined a clinical autism assessment with a developmental measure to evaluate whether high autistic traits were also present in childhood. This found that although around 50% of adolescent girls with AN presented with currently high levels of autistic traits, when combined with the developmental measure, 10% of the sample met diagnostic criteria for an autism diagnosis (Westwood, Mandy, Simic, & Tchanturia, 2017). Making this distinction is important, as features associated with AN such as starvation and depression may produce a pseudo-autistic presentation, in the absence of a developmental history of autistic traits (Hiller & Pellicano, 2013; Treasure, 2013; Treasure, et al., 2020).

There is much less research on whether there is a heightened prevalence of autism in other EDs (Nickel, et al., 2019). Only one study has used an established clinical assessment (the RAADS-R), finding heightened autistic traits in 28% of participants with AN, 40% in BN, and 31% in BED (Vagni, et al., 2016). There is also evidence that autism prevalence may be heightened in children and adolescents receiving treatment for ARFID compared to the other ED diagnoses (Nicely, et al., 2014). As the prevalence of autism, and potential shared characteristics, is less well-characterised in other EDs, the current thesis will predominantly focus on autism and AN. Similarly, there is a lack of research on the ED/autism link from the perspective of autism: the majority of studies are on autism prevalence in EDs, rather than ED prevalence in autism. One study examining EDs in autism and

attention deficit hyperactivity disorder (ADHD) found that 10.8% of the autistic adults reported a current or previous ED, and 20% reported moderate to severe levels of ED symptomatology (Karjalainen, et al., 2016). There is also evidence that autistic adults are less likely to have a healthy BMI compared to non-autistic peers, and are more likely to be underweight, overweight or obese (Sedgewick, Leppanen & Tchanturia, 2019). Interestingly, in the autism and ADHD sample, overall the male:female ratio of participants reporting EDs was 2:5, suggesting that the ED gender ratio may be less skewed in this population (Karjalainen, et al., 2016). Despite this, to date research on autism in EDs has been performed almost exclusively in female populations (Westwood & Tchanturia, 2017).

1.5.3 Research Representation

There is a growing awareness of the heightened prevalence of autism in AN, and increasing research in this area. However, the significance of co-occurring autism is under-represented in broader research in AN, particularly in the development of existing treatments. The treatment of AN in the UK is based in the recommendations of the NICE guidelines (NICE NG69, 2017). Of the 23 RCTs included in the evidence review for the development of these guidelines (summarised in Table 1, follow-up studies not included), autism or autistic traits were only mentioned in one study (Herscovici, Kovalskys & Orellana, 2017). This study highlighted that one of their participants presented with high autistic traits in an example treatment vignette, but did not discuss the impact of these traits on treatment. It is possible that some autistic participants were excluded from the other studies as having a serious medical or psychiatric condition, although no study specified autism as an exclusion criterion. In the development of the NICE guidelines on treating EDs and comorbid long-term health conditions, autism was listed as a potential condition which could require modifications. However, no published studies on this topic were identified, and autism is not mentioned in the final set of recommendations. Consequently, the under-representation of autistic people in the AN treatment literature means that the applicability of existing interventions for autistic patients has not been evaluated. This is significant in the context of research suggesting that autistic people with AN may have unique presentations and needs compared to their non-autistic peers.

1.5.4 Presentation

Co-occurring autism in AN is associated with more severe illness presentations: in women accessing inpatient treatment, higher autistic traits are associated with more severe ED symptomatology, higher levels of depression and anxiety, and poorer work and social functioning (Tchanturia, et al., 2019). Elevated autistic traits in AN are also associated with difficulties in social interaction, reduced

cognitive and affective empathy, heightened cognitive rigidity and obsessive-compulsive symptoms, and higher levels of alexithymia (Anckarsater, et al., 2012; Kerr-Gaffney, Harrison & Tchanturia, 2020; Hobson, et al., 2020; Westwood, Mandy & Tchanturia, 2017a, Westwood, Mandy & Tchanturia, 2017b). There is also some evidence that autistic people with AN may be more likely to meet criteria for obsessive-compulsive and avoidant personality disorders (Anckarsater, et al., 2012).

Significantly, the presence of cognitive rigidity, relationship difficulties, and emotional dysregulation have all been identified as potential developmental and maintaining factors in the cognitive-interpersonal model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). In line with this model, autistic people with AN are more likely to experience poorer illness outcomes, including persisting mental health problems and social difficulties (Nazar, et al., 2018; Nielsen, et al., 2015; Wentz, et al., 2009). Additionally, neuropsychological characteristics associated with autism are associated with longer illness durations in AN (Saure, et al., 2020).

To date, research on the significance of autistic traits in co-occurring autism and AN has primarily focused on the implications of neuropsychological and/or socio-emotional factors. Other ways in which autism could potentially impact the presentation of AN are under-explored. Autism is closely related to eating difficulties distinct from ED pathology. For example, food selectivity is common in children on the autism spectrum, and may put the child at risk of an inadequate nutritional intake (Bandini, et al., 2010; Cermak, Curtin & Bandini, 2010; Nadon, et al., 2011). Although the majority of research on eating in autism is based on child samples, eating difficulties do appear to be more common in autistic adults compared to non-autistic peers (Rastam, 2008; Karlsson, Rastam & Wentz, 2013).

One key factor identified as contributing towards eating difficulties in autistic people is that of sensory problems (Cermak, et al., 2010; Karlsson, et al., 2013). However, the implications of sensory sensitivity for the presentation of AN in autistic people is under-explored. Sensory difficulties are common in autism, and have now been included as a diagnostic criterion in the most recent edition of the DSM (APA, 2013; Robertson & Baron-Cohen, 2017). Around 95% of autistic adults and children exhibit atypical sensory processing (Crane, Goddard & Pring, 2009; Tomchek & Dunn, 2007). Evidence suggests that these differences in autism are associated with alterations in bottom-up processing in the brain, and appear to occur across the different sensory modalities (Robertson & Baron-Cohen, 2017). Significantly, sensory differences in autistic children are thought to be a key contributing factor to the heightened prevalence of eating difficulties in this group compared to their non-autistic peers (Bandini, et al., 2010; Cermak, et al., 2010; Nadon, et al., 2011). The presence of atypical sensory processing may lead autistic children to restrict their food intake to

manage their sensory differences, such as only eating tolerable textures (Williams, Dalrymple & Neal, 2000). Additionally, difficulties with processing internal sensations (known as interoception) could contribute to eating difficulties by making it harder for autistic people to detect if they are hungry or full, although studies on whether interoception is altered in autism have yielded mixed results (Garfinkel, et al., 2016; Nicholson, et al., 2018; Shah, et al., 2016). At present there is a lack of research on how sensory processing impacts eating in autistic adults. A new study does suggest that sensory sensitivities do continue to contribute to food selectivity in autistic adults, but that adults are better able to develop coping strategies for these difficulties (Folta, et al., 2020).

Interestingly, sensory difficulties have also been documented in AN. People with AN consistently self-report heightened levels of sensory sensitivity to external stimuli and sensory avoidance (Bell, Coulthard & Wilbur, 2017; Brand-Gofelth, et al., 2016; Merwin, et al., 2013; Zucker, et al., 2013). Research on interoception suggests that people with AN subjectively experience difficulties detecting feelings of hunger and fullness (Jenkinson, Taylor & Laws, 2018). Research on whether people with AN experience objective differences in sensory sensitivity at the level of sensory detection is less clear. A systematic review highlighted that there is experimental evidence for both heightened and lowered smell sensitivity in AN (Islam, et al., 2015). Whilst the literature on taste in AN had not been synthesised prior to the current thesis, there is also evidence for heightened, lowered, or no apparent differences in taste sensitivity (Aschenbrenner, et al., 2008; Fernandez-Aranda, et al., 2016; Goldzak-Kunik, et al., 2013). Understanding this area is particularly important as neurobiological models of AN maintenance posit that altered sensitivity could potentially play a maintaining role in dietary restriction (Kaye, et al., 2013). Finally, there is also disagreement in the literature on whether people with AN experience objective differences in interoception (Pollatos, et al., 2008; Richards, et al., 2019).

Therefore, further exploring sensory sensitivities and autism in AN could illuminate whether sensory sensitivities are common across autism and AN, potentially representing a shared mechanism, or whether sensory problems represent a difference between these two conditions. If sensory problems represent a difference, this could suggest that autistic people with AN present with unique sensory needs that require adaptation. Additionally, a more detailed understanding of the role autism plays in eating behaviours in adults could illuminate factors contributing to disordered eating in autistic people with AN unrelated to traditional ED pathology.

1.5.5 Risk of Health Inequalities

The significance of health inequalities in autism is an increasingly important topic in the wider research literature. Autistic adults experience significantly increased rates of all major mental health

conditions, and nearly all physical health conditions, compared to their neurotypical peers (Croen, et al., 2015). A Swedish-based study found that life expectancy for autistic people without an intellectual disability was 53.87 years compared to 70.20 years for non-autistic people (Hirvikoski, et al., 2016). Life expectancy for autistic people with an intellectual disability was 39.50 years. This study also found that the lowered expectancy was linked with the heightened prevalence of medical conditions in autistic people. In particular, autistic people were at higher risk of death by suicide, a finding reflected in other research suggesting that autistic adults are more likely to experience suicidal ideation (Cassidy, et al., 2014).

Healthcare access and experience is one factor that underlies these poorer outcomes. Autistic adults report high unmet healthcare needs and lower satisfaction with clinician communication when accessing health services, and are more likely to only access healthcare in the case of an emergency (Nicolaidis, et al., 2013; Tint & Weiss, 2018). Healthcare settings themselves present a barrier to accessing care: loud or busy treatment environments can cause problems for individuals who experience sensory difficulties, and interfere with communication abilities (Neil, Olsson & Pellicano, 2016). In England legislation has been passed in an attempt to address these inequalities. The Autism Act (2009) mandates the government to publish and regularly review an autism strategy for meeting the needs of autistic adults in England. Public bodies, including the NHS, have a legal duty to act under this guidance. The most recent autism strategy and accompanying statutory guidance on implementation states that the NHS must provide staff likely to work with autistic people with appropriate training, and that autistic people must have equal access to psychological services (Department of Health, 2015a; HM Government, 2014). It also highlights that mental health services must make reasonable adjustments for autistic people. Furthermore, the NICE guidelines for autism recommend that autistic people experiencing co-occurring mental health problems should receive adapted psychological interventions delivered by clinicians with an understanding of autism and the implications for treatment (NICE CG142, 2016).

The inclusion of specific guidance for mental health services in these documents reflects the fact that autistic people are at higher risk of experiencing mental health difficulties compared to the general population (Croen, et al., 2015; Lai, et al., 2019). A recent meta-analysis found prevalence estimates of 20% for anxiety disorders, 11% for depressive disorders and 9% for obsessive-compulsive disorder (Lai, et al., 2019). In this context, research in these areas has explored how psychological interventions for these conditions can best be adjusted for autistic people. This research has predominantly focused on adaptations for CBT. Traits associated with autism, including cognitive rigidity, difficulties identifying emotions, and social communication difficulties, may make it harder for autistic people to engage in CBT and result in poorer outcomes (Berthoz & Hill, 2005;

Lickel, MacLean, Blakeley-Smith & Hepburn, 2012; Narzisi, et al., 2012). Studies suggest that whilst CBT appears to be an effective intervention for autistic people, its efficacy may be enhanced by adjustments that recognise the potential role of autistic traits in treatment (Lang, et al., 2010; Spain, et al., 2015). In the UK, NICE recommends that autistic individuals with co-occurring mental health conditions be offered psychological interventions as recommended by the guidance for the specific condition, and that any CBT interventions should include the following adaptations (NICE CG142, 2016):

- A more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and “tool boxes”).
- Placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention.
- Making rules explicit and explaining their context.
- Using plain English and avoiding excessive use of metaphor, ambiguity and hypothetical situations.
- Involving a family member, partner, carer or professional (if the autistic person agrees) to support the implementation of an intervention.
- Maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information).

However, the evidence base for CBT adaptations for autistic people is not based in any studies in EDs (Walters, Loads & Russell, 2016). Therefore, they do not address difficulties that may be specific to CBT-E treatment for AN, including meal planning and food exposure. Moreover, NICE recommends a number of other treatments for AN, including MANTRA and SSCM, which have not been explored in the context of applicability for autistic people. This is important as treatment for AN incorporates a number of features, in particular nutritional rehabilitation, that may present challenges to autistic people not addressed by previous research in adapting psychological therapies for other conditions.

Therefore, despite evidence suggesting that autistic people benefit from adapted psychological interventions, and legal mandates that the NHS must ensure equal access to services for this population, to date there is a lack of research on the implications for ED treatment. This is important as there is evidence that autistic people with AN are at risk of poorer ED treatment outcomes. The small number of outcome studies performed in this area do suggest that people with a diagnosis of autism, or high autistic traits, may experience poorer treatment outcomes in the absence of

appropriate adaptations (Nazar, et al., 2018; Stewart at al., 2017; Tchanturia, Larsson & Adamson, 2016). Even if ED symptoms are reduced, autistic people with AN may experience enduring difficulties related to their autistic traits, particularly in the areas of social and emotional functioning (Nazar, et al., 2018). Case studies suggest that these poorer treatment outcomes may be related to the heightened cognitive rigidity in this population, and communication difficulties (Dandil, Baillie & Tchanturia, 2019; Dudova, Kocourkova & Koutek, 2015).

1.5.6 Implications for Treatment

Despite evidence that autistic people may require adaptations to achieve equitable ED treatment experiences and outcomes, there is a lack of research on what kinds of adaptations might be most beneficial for this population. Adaptations recommended by previous studies include individual rather than group treatment, longer treatment durations, or more intensive care (Nazar, et al., 2018; Stewart, et al., 2017; Tchanturia, Larsson & Adamson, 2016). Additionally, it is possible that some existing ED treatments may be appropriate for autistic people with AN. With the cognitive-interpersonal maintenance model of AN suggesting that cognitive rigidity and difficulties in emotion regulation may be core to the development and maintenance of the illness, a number of treatments have been developed to target these modalities. These include individual psychotherapy in the form of MANTRA, or low-intensity approaches such as individual or group format CRT, and individual format cognitive remediation and emotion skills training (CREST) (Schmidt & Treasure, 2006; Tchanturia, Lounes & Holttum, 2014; Tchanturia, Doris, Mountford & Fleming, 2015; Treasure & Schmidt, 2013). CRT for AN targets cognitive flexibility, decreasing detail-focused thinking styles, and decreasing perfectionistic thinking styles (Tchanturia, et al., 2014). CREST incorporates CRT but includes interventions targeting emotion processing difficulties, including emotion recognition, management and expression (Tchanturia, et al., 2015). It is therefore possible that these kinds of interventions may benefit autistic people with AN, as they already target difficulties associated with autism including cognitive rigidity and emotional dysregulation (Treasure, 2012). However, only CRT has been investigated in relation to autistic traits in AN. These studies suggest that individual CRT, rather than group interventions, may be most effective for patients with high autistic traits (Dandil & Smith, et al., 2020; Tchanturia, Larsson & Adamson, 2016).

In summary, treatment adaptations for autistic people with AN have not previously been explored in-depth, despite evidence that this group may be at risk of poorer outcomes. Whilst research indicates that autistic people with AN may have specific needs that require adaptations, to date this has not been synthesised with studies exploring clinical expertise and patient views on this area. Consequently, treatments for this population may not represent evidence-based practice (Peterson,

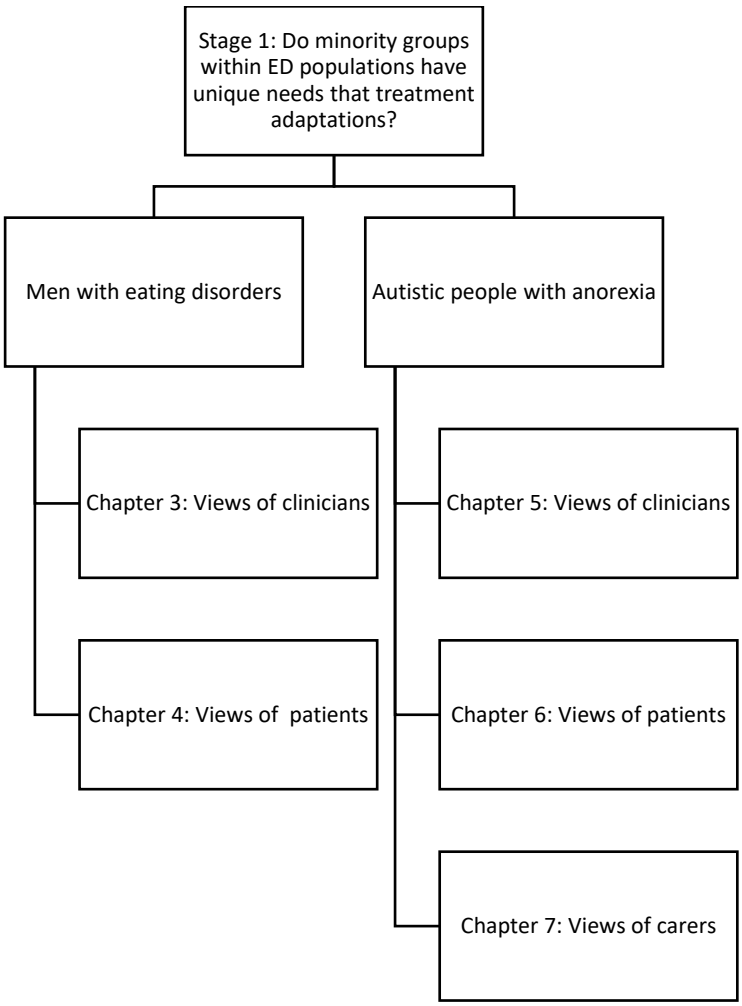
et al., 2016). Additionally, the research evidence itself requires further extension. Exploring the best approach to adapting treatments to this population may first require a more detailed understanding of how the presence of co-occurring autism impacts the presentation of AN. For example, the presence of sensory difficulties could have implications for psychological formulation, the treatment environment, and any dietary interventions.

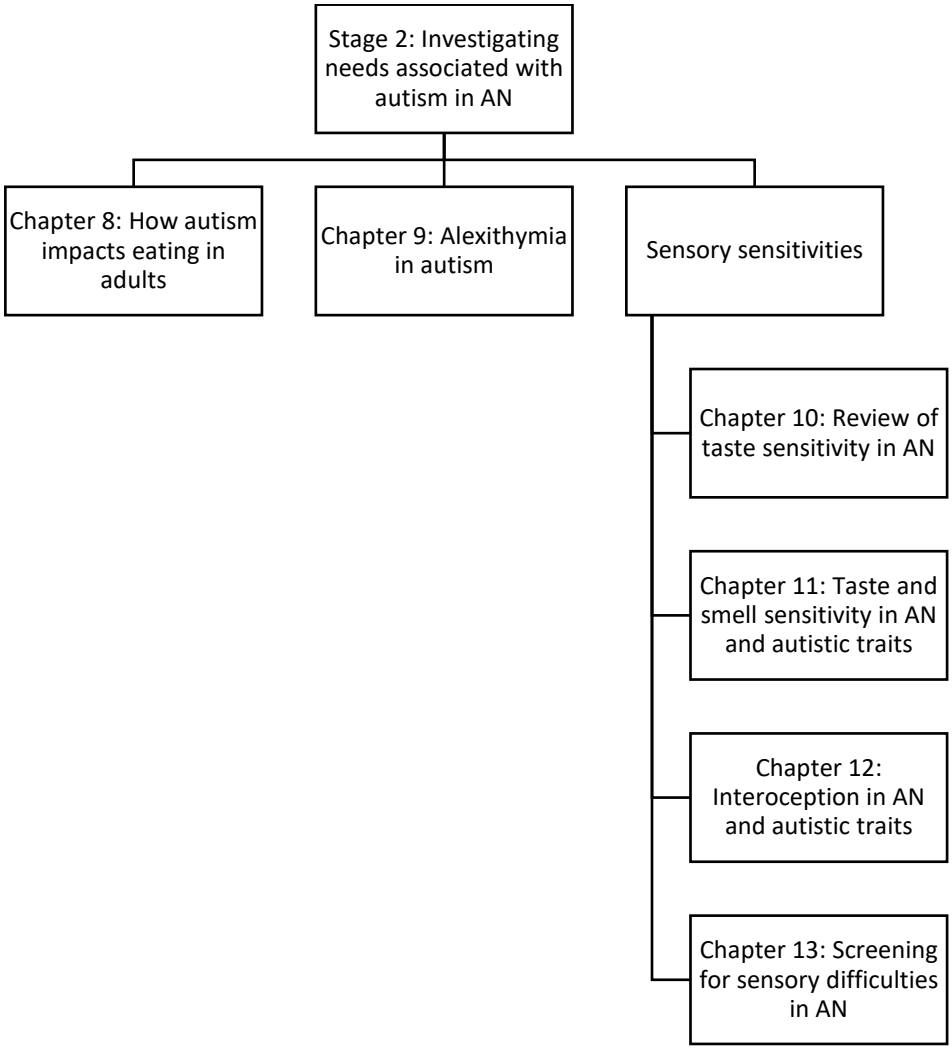
1.6 Thesis Overview

The overall aim of this thesis was to explore whether under-recognised minority groups within the wider ED population have unique features that could require treatment adaptations. The thesis focused on two groups: men with EDs, and autistic people with AN. A visual overview of the thesis is summarised in Figure 1.

Figure 1

Thesis Maps





The first stage of the thesis used qualitative interview methods to explore the views of stakeholders on whether these groups have unique features that require adaptations. This qualitative stage guided the topics identified for further exploration in stage 2. Chapter 3 represents a pilot study exploring the views of clinicians on whether men require different ED treatment approaches compared to women, and if so what kinds of adaptations are beneficial. Chapter 4 continues this topic using interviews with men who had experienced ED treatment. These studies suggested that men do not require fundamentally different treatment approaches on account of their sex, although it did highlight questions about how men can best be made to feel included in a female-dominated field. Chapter 5 is an additional pilot study exploring the views of clinicians on treatment adaptations for autistic people with AN, and found a majority of clinicians believed that adaptations are required but lacked confidence in treating this population. Chapter 6 presents interviews with people with AN and either high autistic traits, or an existing autism diagnosis. The findings of this study strongly suggested that autistic people with AN experience unique needs associated with their autism that are not met by standard treatment approaches, with suggestions for potential adaptations. Topics

raised by clinicians and autistic people with AN in this qualitative stage included a need to understand the impact autism can have on eating in adults, the role of emotion recognition problems, and the role of sensory problems in this population. As interviews with clinicians and patients suggested a number of problems with using standard ED treatment approaches for autistic people with AN, this area was additionally explored using interviews with carers (Chapter 7). These reinforced that existing approaches may not meet the needs of autistic patients, and highlighted problems with accessing appropriate treatment services and the impact of this process on carers.

Therefore, whilst the findings on male EDs suggested that men do not require fundamentally different treatment approaches, the findings on autism and anorexia indicated that this population do have specific needs that require adaptations. These findings guided the second stage of the thesis, which aimed to further investigate these potentially unique needs in autistic people with AN. In Chapter 8, interviews with autistic people explore how autism continues to impact eating behaviours into adulthood. Chapter 9 presents a review and meta-analysis of studies on alexithymia in autism, demonstrating that emotion recognition difficulties are very common in this population. Finally, the thesis investigates the relationship between sensory sensitivity and autistic traits in AN, and explores implications for treatment. In Chapter 10, the current literature on taste sensitivity in AN is reviewed, highlighting that whilst there is some evidence that taste sensitivity is altered in AN, there are methodological inconsistencies and no research on the potential role of autistic traits. Chapter 11 presents the results of a study investigating whether altered taste and smell in AN are associated with autistic traits, finding no relationship. Chapter 12 explores whether altered interoception in AN is associated with autistic traits, and the potential moderating variable of alexithymia in this relationship. Whilst no relationship is found, the study suggests that people with AN may lack insight into their interoceptive abilities. Finally, the thesis explores the potential clinical translation of this research by evaluating the use of a brief, pragmatic sensory screener in ED treatment settings, and the relationship of self-rated sensitivity to autistic traits (Chapter 13).

1.6.1 Aims and Hypotheses

1.6.1.1 Chapter 3 (Kinnaird & Norton, Tchanturia, 2018). Aim: To explore clinician views on whether men with EDs have unique needs that require treatment adaptations.

1.6.1.2 Chapter 4 (Kinnaird, Norton, Pimblett, et al., 2019a). Aim: To explore the views of men with EDs on whether they have unique needs that require treatment adaptations.

1.6.1.3 Chapter 5 (Kinnaird, Norton & Tchanturia, 2017). Aim: To explore clinician views on whether autistic people with AN have unique needs that require treatment adaptations.

1.6.1.4 Chapter 6 (Kinnaird, Norton, Stewart, et al., 2019). Aim: To explore the views of autistic people with AN, or people with AN and high autistic traits, on whether they have unique needs that require treatment adaptations.

1.6.1.5 Chapter 7 (Adamson & Kinnaird, et al., 2020). Aim: To explore the views of carers on whether autistic people with AN have unique needs that require treatment adaptations.

1.6.1.6 Chapter 8 (Kinnaird, Norton, Pimblett, et al., 2019b). Aim: To explore with autistic people how autism impacts eating in adults.

1.6.1.7 Chapter 9 (Kinnaird, Stewart & Tchanturia, 2019). Aim: To systematically evaluate and meta-analyse studies that have used the Toronto Alexithymia Scale (TAS) to explore whether alexithymia is elevated in autism compared to HC.

1.6.1.8 Chapter 10 (Kinnaird, Stewart & Tchanturia, 2018). Aim: To systematically evaluate the literature on whether taste sensitivity is altered in AN compared to HC.

1.6.1.9 Chapter 11 (Kinnaird, Stewart & Tchanturia, 2020a). Aims: 1) To investigate whether taste and smell sensitivity is altered in AN compared to HC, 2) to explore the relationship between taste and smell sensitivity and autistic traits in AN. In the context of previous mixed findings in the area of sensory sensitivity in AN, this study did not generate specific hypotheses prior to data collection.

1.6.1.10 Chapter 12 (Kinnaird, Stewart & Tchanturia, 2020b). Aims: 1) To investigate whether interoception is altered in AN compared to HC, 2) to explore the relationship between interoception, autistic traits and alexithymia in AN. Hypotheses: 1) People with AN would exhibit lowered interoceptive accuracy compared to HC. 2) People with AN would self-report lowered interoceptive sensibility compared to HC. 3) People with AN would exhibit poorer interoceptive awareness compared to HC. 4) There would be an association between interoceptive accuracy, alexithymia and autism within the AN group.

1.6.1.11 Chapter 13 (Kinnaird, Dandil, et al., 2020). Aims: 1) To pilot the use and acceptability of a brief screening measure for sensory problems in an ED treatment service, 2) to assess whether self-rated sensory sensitivities in AN are related to autistic traits.

Table 1

Summary of psychological intervention clinical trials used in the development of NICE guidelines for ED treatments, including proportion of male participants included in each study.

Diagnosis group	Study	Intervention	Comparison Intervention	Male participants (%)
Anorexia Nervosa	Agras, et al., 2014	Family based therapy	Systematic family therapy	11%
	Dare, et al., 2001	General psychodynamic psychotherapy	Psychiatric counselling, family therapy	2%
	Dalle-Grave, et al., 2013	CBT-E	Different version of CBT-E	22%
	Eisler, et al., 2000	Family therapy	Different version of family therapy	2%
	Eisler, et al., 2016	Family therapy	Different version of family therapy	9%
	Fichter, et al., 2012	Internet guided self-help	Treatment as usual	0%
	Geist, et al., 2000	Family therapy	Family group psychoeducation	0%
	Godart, et al., 2012	Family therapy and treatment as usual	Treatment as usual	0%
	Hall & Crisp, 1987	Combined family therapy and interpersonal psychotherapy versus	Nutritional counselling	0%

Herscovici, et al., 2017	Family therapy with family meal	Family therapy without family meal	4%
Lock, et al., 2005	Long term family therapy	Short term family therapy	10%
Lock, et al., 2010	Adolescent-focused psychotherapy	Family therapy	9%
McIntosh, et al., 2005	CBT-E	Interpersonal psychotherapy, specialist supportive clinical management	0%
Pike, et al., 2003	CBT-E	Nutritional counselling	0%
Robin, et al., 1999	Adolescent-focused psychotherapy	Family therapy	0%
Russell, et al., 1987	Supportive therapy	Family therapy	9%
Schmidt, et al., 2012	MANTRA	Specialist supportive clinical management	8.8%
Schmidt, et al., 2015	MANTRA	Specialist supportive clinical management	1.4%
Touyz, et al., 2013	CBT-E	Specialist supportive clinical management	0%

	Treasure, et al., 1995	Specialist supportive clinical management	General psychodynamic psychotherapy	0%
	Whitney, et al., 2012	Individual family work	Family day workshops	2%
	Zipfel, et al., 2014	CBT-E	Focal psychodynamic therapy	0%
Bulimia Nervosa	Agras, et al., 1989	CBT-E	Wait list, self-monitoring	0%
	Agras, et al., 2000	CBT-E	Interpersonal psychotherapy	0%
	Bailer, et al., 2004	Guided self-help	CBT group therapy	0%
	Banasiak, et al., 2005	Guided self-help	Wait list control	0%
	Bauer, et al., 2012	Text messaging intervention	Wait list control	0%
	Bulik, et al., 1998	CBT-E	Different versions of CBT-E	0%
	Carter, et al., 2003	Self-help for EDs	Wait list control, general self help	0%
	Chen, et al., 2003	CBT-E	CBT-E, group version	0%
	Cooper, et al., 1995	CBT-E	Behavioural therapy	0%
	Durand & King, 2003	Guided self-help	Combined CBT and interpersonal therapy	0%

Fairburn, 1986	CBT-E	Psychodynamic therapy	0%
Fairburn, et al., 1991	CBT-E	Behavioural therapy, interpersonal psychotherapy	0%
Fairburn, et al., 2009	CBT-E	Wait list control, other version of CBT	4%
Fairburn, et al., 2015	CBT-E	Interpersonal psychotherapy	2%
Freeman, et al., 1988	CBT-E	Wait list control, behavioural therapy, nutritional counselling	0%
Garner, et al., 1993	CBT-E	Dynamic psychotherapy	0%
Griffiths, et al., 1994	CBT-E	Wait list control	0%
Hsu, et al., 2001	CBT-E	Nutrition counselling, support group	0%
Lavender, et al., 2012	Group CBT-E	Emotional and social mind training	8%
Lee & Rush, 1986	Group CBT-E	Wait list control	0%
Le Grange, et al., 2007	Supportive psychotherapy	Family therapy	2%

Le Grange, et al., 2015	CBT-E	Family therapy, supportive psychotherapy	6%
Leitenberg, et al., 1988	Group behavioural therapy	CBT group therapy, wait list control	0%
Ljotsson, et al., 2007	Guided self-help	Wait list control	6%
Mitchell, et al., 1993	Group CBT-E	Group CBT-E, different version	0%
Mitchell, et al., 2008	CBT-E	Guided self-help	0%
Nauta, et al., 2001	Group behavioural therapy	Group nutritional counselling	0%
Nevonen & Broberg, 2006	Hybrid-mixes/ sequences therapies	Other hybrid	0%
Olmsted, et al., 1991	CBT-E	Group psychoeducation	0%
Palmer, et al., 2002	Guided self help	Wait list control	1%
Poulsen, et al., 2014	Dynamic psychotherapy	CBT-E	3%
Ruwaard, et al., 2013	Online self-help	Self-help, wait list control	3%
Sanchez-Ortiz, et al., 2011	Online guided self-help	Wait list control	1%
Schmidt, et al., 2007	CBT-E	Family therapy	2%

	Steele & Wade, 2008	Guided self-help ED	Guided self-help for perfectionism, placebo	1%
	Thackwray, et al., 1993	CBT-E	Behavioural therapy, placebo	0%
	Thompson-Brenner, et al., 2016	CBT-E	Other version of CBT-E	0%
	Treasure, et al., 1994	CBT-E	Wait list, self-help	0%
	Wagner, et al., 2013	Self-help (internet)	Guided self-help	0%
	Walsh, et al., 2004	Guided self-help	Placebo	0%
	Wilson, et al., 1991	CBT-E	Other version of CBT-E	10%
	Wolf & Crowther, 1992	Group CBT-E	Behavioural group therapy, wait list control	0%
	Wonderlich, et al., 2014	Integrative cognitive-affective therapy	CBT-E	10%
Binge Eating Disorder	Agras, et al., 1994	CBT-E group	Self-help and group therapy, group therapy and pharmacotherapy	0%
	Alfonsson, et al., 2015	Behavioural therapy group	Wait list controls	6%

Carrard, et al., 2011	Guided self-help	Wait list controls	0%
Carter & Fairburn, 1998	Guided self-help	Self-help, wait list controls	0%
Cassin, et al., 2008	Guided self-help	Self-help	0%
Castelnuovo, et al., 2011	Combined CBT-E and weight loss group	Combined brief strategic thinking and weight loss group	0%
DeBar, et al., 2011	Guided self-help	Treatment as usual	0%
DeBar, et al., 2013	CBT-E	Treatment as usual	0%
Dunn, et al., 2006	Guided self-help	Self help	11%
Fischer, et al., 2014	CBT-E	Wait list control	12%
Grilo & Masheb, 2005	Guided self-help	Other guided self-help	21%
Grilo, et al., 2011	CBT-E group	Behavioural therapy group	38%
Grilo, et al., 2013	Self-help ED	Treatment as usual	21%
Hilbert & Tuschen-Caffier, 2004	CBT-E group (body exposure)	CBT-E group (cognitive)	0%

Hill, et al., 2011	Dialectical behaviour therapy	Wait list control	0%
Jones, et al., 2008	Internet self-help	Wait list controls	27%
Kristeller, et al., 2014	Mindfulness	CBT-E, wait list control	12%
Loeb, et al., 2000	Guided self-help	Self-help	0%
Masson, et al., 2013	Guided self-help	Wait list controls	12%
McIntosh, et al., 2016	CBT-E	General CBT, behavioural therapy	0%
Munsch, et al,. 2007	CBT-E group	Behavioural therapy group	9%
Nauta, et al., 2000	CBT-E group	Behavioural therapy group	0%
Peterson, et al., 2001	Group psychoeducation	Group guided self-help, group self-help	0%
Peterson, et al., 2009	Group psychoeducation	Group guided self-help, group self-help, wait list controls	12%
Ricca, et al., 2010	CBT-E	CBT-E group	14%
Safer, et al., 2010	Behavioural therapy	Group counselling	14%

Shapiro, et al., 2007	Guided self-help	Group CBT, wait list controls	8%
Striegel-Moore, et al., 2010	Guided self-help	Treatment as usual	8%
Telch, et al., 1990	CBT-E group	Wait list controls	0%
Wilfley, et al., 1993	Interpersonal psychotherapy group	CBT-E group, wait list controls	0%
Wilfley, et al., 2002	CBT-E group	Interpersonal psychotherapy group	17%
Wilson, et al., 2010	Interpersonal patient therapy	Guided self-help, behavioural weight loss	15%

Chapter 2: Research Methods

This chapter provides an overview of the general methodology used in this thesis. The methods for each individual study are outlined in more detail in each chapter. The chapter begins by outlining the overall thesis design before proceeding to detail participants, inclusion and exclusion criteria, and recruitment strategies. Information about ethical approvals and considerations are included. Interview schedule development is detailed for the qualitative studies and outcome measures are summarised for the quantitative research. Finally, the chapter gives an overview of general study procedures and analysis strategies.

2.1 Design

The first stage of the thesis used a qualitative approach. Initially, clinicians were interviewed as part of a pilot study exploring their perspectives and experiences of treatment adaptations for men with EDs, and autistic people with AN (Chapters 3 & 5). These findings were then used to guide interview schedule development for subsequent studies exploring the views and treatment experiences of patients and carers (Chapters 4, 6 & 7).

The findings from this stage were then used to guide the priorities of the second stage of the thesis. With the first stage suggesting that a need for treatment adaptations may be more relevant for autistic people with AN, compared to men with EDs, the second stage focused on autistic people with AN only. This phase used a mixed-methods design. A qualitative interview design was retained for Chapter 8, interviewing autistic people about their eating behaviours. The literature on alexithymia in autism was synthesised using a systematic review and meta-analysis (Chapter 9), and a second systematic review summarised research on taste sensitivity in AN (Chapter 10). Chapters 11 and 12 used a case-control design to explore sensory sensitivity in AN, with regression analyses used to assess associations with autistic traits. Chapter 13 used a cross-sectional design to pilot a sensory screening measure in an ED service, assessing self-rated sensory sensitivity in AN and the role of autistic traits.

2.2 Participants

Participants included in the studies, and recruitment approaches, are summarised in Table 1. All studies included adults only (aged over 18) with a sufficient level of English fluency to participate in study procedures. Due to the nature of the tasks, the case-control studies had the additional exclusion criteria of no neurological conditions, serious medical conditions, or medical conditions affecting taste or smell (for the taste and smell experiments only).

Table 1

Summary of participant samples across the thesis studies.

Chapter	Design	Inclusion Criteria	Recruitment
3: Clinician views on treatment needs of men with EDs	Qualitative interviews	Clinicians (any discipline) with minimum 3 years of experience working in ED field	Clinicians currently working in South London and Maudsley NHS Foundation Trust (SLAM) ED service
4: Patient views on treatment needs of men with EDs	Qualitative interviews	Men with current or previous experience of ED treatment	Men receiving treatment in NHS ED services (referred by treating clinician), advertising on social media
5: Clinician views on treatment needs of autistic people with AN	Qualitative interviews	Clinicians (any discipline) with minimum 3 years of experience working in ED field	Clinicians currently working in SLAM ED service
6: Patient views on treatment needs of autistic people with AN	Qualitative interviews	Autistic people with current or previous experience of treatment for AN OR	People receiving treatment in SLAM ED services (referred by treating clinician),

		people being treated for AN identified by screening tools as presenting with clinically significant levels of autistic traits	advertising on social media
7. Carer views on treatment needs of autistic people with AN	Qualitative interviews	People with previous or current caring responsibilities for an autistic person in treatment for AN	Advertising on social media, carers of patients receiving treatment in SLAM ED services, principle investigator contacts
8. How autism impacts eating in adults	Qualitative interviews	Autistic people, with or without experience of an ED	Participants from a previous online study on eating problems in autistic people who consented to be contacted for future research
11. Taste and smell sensitivity in AN and autistic traits	Case Control	People with a current diagnosis of AN. Healthy controls (HC) with no history of EDs/ mental health problems, and no autism diagnosis	Patients receiving treatment in SLAM ED services (referred by clinicians), online advertising, advertising within university community
12. Interoception in AN and autistic traits	Case Control	People with a current diagnosis of AN. HC with no history of EDs/ mental health problems, and no autism diagnosis	Patients receiving treatment in SLAM ED services (referred by clinicians), online advertising, advertising within

			university community
13. Sensory screening in AN	Cross-sectional	People with a current diagnosis of AN	Patients receiving treatment in SLAM ED services (referred by clinicians)

For the qualitative studies, diagnoses were self-reported only and not confirmed by the researcher. For the case-control studies, diagnoses of AN were confirmed using the Structured Clinical Interview for DSM-5 (SCID-5; First, et al., 2015). HC were screened for any current symptoms or history of mental health problems, including EDs, using the SCID-5. HC were also screened for high autistic traits using the AQ (Baron-Cohen, et al., 2001). For the cross-sectional study, diagnoses of AN were confirmed by the participant's clinicians with reference to their clinical notes.

2.3 Ethical Approval

Ethical approval for the qualitative studies was given by the London-City and East Research Ethics Committee and South London (18/LO/0050) and the Maudsley Clinical Audit & Effectiveness Committee. Ethical approval for the case-control studies was given by the North East Newcastle and North Tyneside 2 Research Ethics Committee (18/NE/0193). The cross-sectional sensory screening study received approval from the Maudsley Clinical Audit & Effectiveness Committee as a service improvement project. Copies of ethical approval letters, patient information sheets and consent forms are located in Appendices A, B and C respectively.

2.3.1 Ethical Considerations

As the qualitative studies on experiences of ED treatment had the potential to involve talking about difficult topics, clinicians were encouraged to only refer patients to this study if they felt that the patient was able to engage in a discussion about their treatment without causing unnecessary distress. For example, clinicians were advised not to refer patients who were currently experiencing suicidal ideation, or who were presenting with other risks that might be exacerbated by discussing their experiences. Participants were also fully briefed about the nature of the interview and the questions before they gave informed consent, and it was made clear that no questions were compulsory and that they could stop the interview at any point. In addition, participants taking part in all studies were directed to an ED charity website (www.beateatingdisorders.org.uk) for further support at the end of the study session.

Chapters 10 and 11 involved screening for high autistic traits in people with AN using a gold-standard measure (the Autism Diagnostic Observation Schedule (ADOS; Lord, et al., 2000). Therefore, there was a possibility that individuals with no diagnosis of autism might score above the clinical threshold on this measure, indicating that the individual might benefit from further assessment. This was addressed in two ways. Firstly, participants with AN were advised that, used in isolation, the ADOS cannot be used to make a diagnosis of autism. Therefore, an ADOS assessment would only indicate potential high autistic traits rather than providing a diagnosis. Secondly, ethical permission was obtained to communicate the results of the ADOS to the participant's clinical team if they were found to score above the clinical threshold, to allow their clinical team to make appropriate decisions around referral and potential implications for ED treatment. Participants gave written permission for the study team to contact their clinicians on the consent form.

2.3.2 Informed Consent

Participants recruited from ED services were informed about the study by a member of their clinical care team. If the participant was an inpatient they were visited at their place of treatment by a researcher to discuss the study and provided with a written information sheet. If the participant was an outpatient, or recruited through online advertising externally to the ED service, they were contacted by the researcher by email to discuss the study and provided with an information sheet. If the participant agreed to participate, they were asked to sign a consent form. Copies of participant information sheets and consent forms are located in Appendices B and C respectively. As Chapter 13 represented a service improvement project with local approval, the sensory screening questionnaire was incorporated into standard clinical practice and so did not require separate consent procedures.

2.4 Interview Schedules

Final interview schedules for the six qualitative studies (Chapters 3-8) are located in Appendix D. Interview schedules were developed individually for each study based on a combination of the research aims (to explore treatment experiences and potential adaptations), and previous literature in these areas. As treatments for autistic people with AN represent an under-researched field, the interview schedule for this study (Chapter 6) was developed with the help of an autistic individual who had previously received treatment for AN. Interview schedules were developed and changed as interviews progressed: where participants raised previously unconsidered topics, these were added to the schedule to explore with future participants.

2.5 Outcome Measures

This section provides an overview of the outcome measures used in the case-control studies (Chapters 11 and 12) and the cross-sectional study (Chapter 13). Not all outcome measures were used in all studies. Table 2 summarises which outcome measures were used in which study. Copies of all questionnaire measures are located in Appendix E.

Table 2

Overview of outcome measures used in Chapters 11-13.

		Chapter 11 (Taste and smell)	Chapter 12 (Interoception)	Chapter 13 (Sensory screening)
Autism measures	Autism Diagnostic Observation Schedule (ADOS)	Yes (but not reported in final study)	Yes (but not reported in final study)	
	Adult Autism Quotient (AQ)	Yes	Yes	
	Adult Autism Quotient- 10 Item (AQ-10)			Yes
Clinical measures	Eating Disorder Examination Questionnaire (EDE-Q)	Yes	Yes	
	Toronto Alexithymia Scale (TAS-20)		Yes	
	Hospital Anxiety and Depression Scale (HADS)	Yes	Yes	Yes
	Weight (BMI)	Yes	Yes	Yes
	Demographics	Yes	Yes	Yes
Sensory measures	Sniffin' Sticks	Yes		

	Taste Strips	Yes		
	Heartbeat tracking task		Yes	
	Sensory Perception Quotient (SPQ)	Yes		
	Body Perception Quotient (BPQ)		Yes	
	Brief Sensory Screener			Yes

2.5.1 Measuring Autistic Traits

2.5.1.1 Autism Diagnostic Observation Schedule- 2nd Edition (ADOS; Lord, et al., 2000). The ADOS is a standardised semi-structured assessment of behaviours and characteristics associated with autism. It assesses the domains of language and communication, reciprocal social interaction, imagination, stereotyped behaviours and restricted interests, and other behaviours associated with autism. It takes around an hour to administer. The ADOS has different modules dependent on the participant's expressive language abilities. All participants in this thesis were assessed using Module 4, designed for use with verbally fluent adolescents and adults. The assessment was scored using the recently updated algorithm (Hus & Lord, 2014). This algorithm is consistent with the updated DSM-5 criteria for autism, and has improved sensitivity and specificity compared to the original scoring. A recent study found that more women with AN score above threshold on the new algorithm compared to the previous algorithm (Sedgewick, et al., 2019). A systematic review of diagnostic assessment tools for autism in AN suggests that to date the ADOS is the most commonly used measure in this population, with the percentage of people with AN scoring above threshold on the algorithm ranging from 10-50% (Bentz, Jepsen, et al., 2017; Mandy & Tchanturia, 2015; Postorino, et al., 2017; Sedgewick, et al., 2019; Westwood, Mandy, Simic & Tchanturia, 2017; Westwood, Mandy & Tchanturia, 2017; Westwood & Tchanturia, 2017).

In the original case-control study designs, the goal was to recruit three equally sized groups: an HC group, an AN group with low autistic traits, and an AN group with high autistic traits. All participants with AN were assessed using the ADOS, with plans to divide participants with AN into these groups based on ADOS scores. However, towards the end of the recruitment period it became apparent that only a third of participants with AN scored above threshold, creating uneven group sizes. In

addition, analyses showed that key sensory outcome scores across the three groups violated the homogeneity of variance assumption. Consequently, ADOS scores were not used in the final analysis. The design and recruitment strategy for the studies was instead adjusted to compare equal sized groups of people with AN to HC, with the role of autistic traits explored using the AQ as a continuous measure within the AN group rather than using the ADOS scores as a categorical measure.

2.5.1.2 Adult Autism Quotient (AQ; Baron-Cohen, et al., 2001). The AQ is a self-report scale designed to measure autistic traits in adults. The original AQ consists of 50 items, with a threshold score for use in case-control populations of 32. A higher score indicates higher autistic traits. At a threshold score of 32, 80% of autistic adults scored above this threshold compared to 2% of matched controls (Baron-Cohen, et al., 2001). More recently a shorter, 10 item version of the AQ has been developed using a threshold score of 6, exhibiting similar levels of sensitivity and specificity (Allison, Auyeung & Baron Cohen, 2012). Both the AQ and the AQ-10 have previously been widely used as a measure of autistic traits in AN, with a meta-analysis suggesting that people with AN have higher mean scores compared to HC (Westwood, Eisler, et al., 2016).

Although the AQ is not intended as a diagnostic tool, the NICE guidelines for autism diagnosis recommend that the AQ-10 should be used as a screening measure for adults with suspected autism, and that adults scoring above threshold should be referred for a full assessment (NICE CG142, 2016). However, this use of the AQ-10 as a referral screening measure has been criticised for reasons that may have particular relevance to its use in AN. Validation studies of the AQ and the AQ-10 suggest that they effectively discriminate between autistic people and controls (Allison, Auyeung & Baron Cohen, 2012; Baron-Cohen, et al., 2001). However, studies in clinical populations suggest that they are not effective in predicting autism diagnosis in adults with suspected autism (Ashwood, et al., 2016; Conner, Cramer & McGonigle, 2019; Sizoo, et al., 2015). In the largest study in this area, AQ and AQ-10 scores were found to not predict eventual autism diagnosis in adult referrals to an autism diagnostic service (Ashwood, et al., 2016). There were no correlations between AQ scores and ADOS scores, indicating that two of the most commonly used measures of autistic traits in AN research lack agreement (Westwood, Eisler, et al., 2016; Westwood & Tchanturia, 2017). Moreover, 64% of individuals scoring below threshold on the AQ were found to be false negatives who did receive an autism diagnosis. These false negatives were more likely to have a comorbid anxiety diagnosis compared to the false positives, suggesting that anxiety might contribute to heightened AQ scores. This is concerning for the use of the AQ in ED services, as estimates suggest that between 60-83% of people diagnosed with AN may also have an anxiety disorder (Godart, et al., 2000; Kaye, et al., 2004; Swinbourne, et al., 2012).

Therefore, in the case-control experimental studies the full AQ was used as a continuous measure of autistic traits only. In the cross-sectional clinical study, the AQ-10 was used as a categorical measure in patients with AN to create two groups (high autistic traits, and low autistic traits). This methodological discrepancy in the thesis reflects the fact that despite concerns, the AQ-10 does continue to be widely used clinically as a screener for high autistic traits as recommended by NICE guidelines. As the cross-sectional study represented an exploration of a sensory screening measure in a clinical setting, the AQ-10 threshold was retained in the study design to reflect its common clinical use.

2.5.2 Measuring Other Variables

2.5.2.1 Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 2008). ED symptoms in the case-control studies were assessed using the EDE-Q. The EDE-Q is a widely used standardised measure of self-reported ED symptoms. Participants respond on Likert scales to 36 items assessing ED cognitions and behaviours over the past 28 days. Higher scores indicate higher frequency of behaviours. Item scores are then used to generate a total "global" score, and four subscale scores measuring Eating Concern, Weight Concern, Shape Concern and Restriction. In the current thesis, only Global scores were included in study outcomes. The EDE-Q has been validated both in community and clinical samples (Dahlgren, Stedal & Ro, 2017; Mond, et al., 2006).

2.5.2.2 Toronto Alexithymia Scale (TAS-20; Bagby, Parker & Taylor, 1994). Alexithymia in the interoception study was assessed using the TAS-20. The TAS-20 is a self-report measure of alexithymia with good reliability and validity that is widely used in both autism and ED research (Bagby, et al., 1994; Berthoz & Hill, 2005; Parker, Taylor & Bagby, 2003; Westwood, Kerr-Gaffney, et al., 2017). The scale consists of 20 items to which participants respond on a Likert scale, with higher scores indicating higher levels of alexithymia. Although the scale does include three subscales (Difficulty Identifying Feelings, Difficulty Describing Feelings, Externally-Orientated Thinking), only total scores were assessed in the current thesis.

2.5.2.3 Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Symptoms associated with anxiety and depression were measured using the HADS. The HADS is a self-report assessment consisting of 14 items. 7 items assess anxiety, and 7 items assess depression. Higher scores indicate higher levels of symptoms, with a clinical threshold of 10 or above for each subscale indicating a possible case. It is widely used, and has been validated both in both clinical and community populations (Bjelland, et al., 2002).

2.5.2.4 Weight. Weights were calculated as body mass indices (BMI). Participant weight and height was either measured on the day of testing, or the most recent BMI calculation was collected from their clinical notes if the participant was receiving ED treatment within SLAM services.

2.5.2.5 Demographics. Participants completed self-report demographic information sheets. These included questions on general demographic information (age, ethnicity, sex), and ED-specific information (treatment status, illness duration, other psychiatric comorbidities). Demographic information sheets were also used to collect information about other medical diagnoses which might impact eligibility (neurological conditions, conditions affecting taste and smell).

2.5.3 Measuring Sensory Outcomes

2.5.3.1 Sniffin' Sticks (Hummel, et al., 1997). Sniffin' Sticks were used as an objective measure of smell sensitivity. This test is validated and widely used, including in the fields of autism and EDs (Islam, et al., 2015; Larsson, Tirado & Wiens; 2017). The standardised Sniffin' Sticks measure is purchased from the manufacturer (Medisense) and consists of sets of pens, with each pen containing a specific scent at a specific strength. The participants are blindfolded throughout. Pens are then placed 2cm in front of the centre of the participant's nostrils for 3 seconds. Sniffin' Sticks assess three domains of smell sensitivity: threshold, discrimination, and identification. Scores are generated for each of the three domains, as well as an overall total score. The maximum score available for each domain is 16, with a maximum total score of 48. A higher score represents higher smell sensitivity, with total scores <30 suggestive of hyposmia and scores <16 suggestive of anosmia (Hummel, Kobal, Gudziol & Mackay-Sim, 2007).

The first task measures smell threshold, operationalised as the strength of smell at which participants are able to detect the scent of *n*-butanol. In a forced-choice paradigm, participants are presented with three pens in a row in a randomised order: one pen contains *n*-butanol, the other two a neutral odour. If the participant identifies the *n*-butanol correctly twice in a row, the presentation is repeated with a set of pens with a less strong *n*-butanol scent. If the participant does not identify the pen correctly, the presentation is repeated with a set of pens with a stronger *n*-butanol scent. Therefore, if a participant consistently detects the *n*-butanol pen correctly, the *n*-butanol scent will become weaker and weaker with successive presentations. A "turning point" occurs when a participant identifies the *n*-butanol scent correctly after successive incorrect identifications, or when a participant identifies the *n*-butanol scent incorrectly after successive correct identifications. The test lasts until the participant has completed seven of these turning points, with the final score representing the mean of the final four turning points.

The second task measures smell discrimination, or the ability to tell the difference between smells. Participants are again presented with three pens in a row in a forced-choice task. Two pens smell the same, and one pen smells differently: the participant is instructed to identify the different pen. This is carried out 16 times. Unlike the *n*-butanol pen used in the smell threshold task, all pens used in the discrimination and below identification task are common smells (for example, the smell of lavender, cinnamon, lemon, or fish).

The third task measures smell identification. Participants are presented with one pen, and asked to identify the smell from a card with four options. This is carried out 16 times with different smells. Again, these smells are all common smells.

2.5.3.2 Taste Strips (Mueller, et al., 2003). Taste Strips were used as an objective measure of taste sensitivity. Also purchased through Medisense, Taste Strips represent a standardised measure previously used in research in both autism and ED fields (Fernandez-Aranda, et al., 2016; Tavassoli & Baron-Cohen, 2012).

Taste Strips are strips of filter paper impregnated with four different taste qualities (sweet, salty, sour, bitter), each with four different concentrations. Therefore, the test involves 16 different strips. Sweet strips are made using different concentrations of sucrose (0.4, 0.2, 0.1, 0.05 grams per millilitre (g/mL)), salty strips use sodium chloride (0.25, 0.1, 0.04, 0.016 g/mL), sour strips use citric acid (0.03, 0.165, 0.09, 0.05 g/mL), and bitter strips use quinine hydrochloride (0.006, 0.0024, 0.0009, 0.0004 g/mL).

Participants were instructed not to eat or drink anything other than water an hour prior towards the test. As the taste test was completed last in a battery of sensory testing lasting an hour and a half to two hours, this was controlled by the researcher. Taste strips were placed once at a time in the centre of the participant's tongue, and participants were instructed to close their mouth. Participants were then asked to remove the strip and identify the taste as sweet, sour, salty, bitter, or no taste. After each strip participants rinsed their mouth with water.

Taste Strips only measure taste identification, providing an overall taste score and sub-scores for sweet, salty, sour and bitter tastes. Correct identifications yielded one point, yielding a maximum score of 16. Maximum scores for each taste quality were 4. A score <9 is considered a sign of hypogeusia (Landis, et al., 2009).

2.5.3.3 Heartbeat tracking task (Schandry, 1981). The heartbeat tracking task was used as a measure of cardiac interoceptive accuracy, and task confidence ratings used as a measure of metacognitive insight into interoceptive abilities (Murphy, Catmur & Bird, 2019). The task was

chosen as it is the most commonly used objective measure of interoception in AN research (Ambrosecchia, et al., 2017; Lutz, et al., 2019; Pollatos, et al., 2008; Pollatos, et al., 2016; Richard, et al., 2019).

In the heartbeat tracking task, participants are instructed to silently count their own heartbeats during four randomised time windows (25, 35, 45, and 100 seconds), and at the end of each window to report the counted heartbeats to the researcher. Participants are additionally instructed not to attempt to measure their heartbeats in any way (for example, by taking their own pulse). Reported heartbeats are then compared to actual number of heartbeats, measured by the researcher using a pulse oximeter attached to the participant's index finger. An interoceptive accuracy score comparing reported to actual (real) heartbeats is then calculated for each window using the formula 1-(|nbeatsreal – nbeatsreported|)/((nbeatsreal + nbeatsreported)/2) (Garfinkel, et al., 2015). Scores for each of the four windows are then averaged to give a single overall score. Following completion of the four windows, participants were asked to rate their confidence in their ability to count their own heartbeats as a score from 0 (no confidence) to 100 (totally confident).

2.5.3.4 Sensory Perception Quotient (SPQ; Tavassoli, Hoekstra & Baron-Cohen, 2014). The SPQ was used as a subjective measure of sensory sensitivity. The SPQ was designed to measure sensory hyper- and hyposensitivity in autistic adults, and has been validated in this population (Tavassoli, et al., 2014). It was used in the present thesis to explore whether these sensory differences associated with autism were also present in AN samples, and to assess any divergence between objective and subjective sensory measures in this population. This was the first use of the SPQ in an ED population.

The SPQ consists of 92 items, each representing a statement about sensory sensitivity (for example, "I would be able to smell the smallest amount of burning from anywhere in the house"). The SPQ covers the five basic sensory domains: smell, touch, taste, vision, and hearing. Participants respond to each item on a Likert scale, indicating if they agree or disagree with the statement. Higher scores indicate hyposensitivity (low sensitivity), and lower scores indicate hypersensitivity (high sensitivity). Scores can be generated both for the individual sensory domains, and as an overall total.

2.5.3.5 Body Perception Questionnaire (BPQ; Porges, 1993). The awareness subscale of the BPQ was used as a measure of subjective perception of interoceptive aptitude (Garfinkel, et al., 2015). Previous studies on subjective interoception in the ED field have used the interoceptive subscale of the Eating Disorder Inventory (EDI; Garner, Olmstead & Polivy, 1983; Jenkinson, et al., 2018). However, this subscale has been criticised for measuring insight into physical sensations associated with emotions only, rather than representing a broader measure of somatic awareness

(Eshkevari, Rieger, Musiat & Treasure, 2014). The BPQ was selected as it has previously been used together with the heartbeat tracking task to assess interoception in a number of studies, including in autistic populations (Garfinkel, et al., 2015; Garfinkel, et al., 2016). The subscale consists of 45 items listing bodily sensations (for example, "my skin itching"). Participants are instructed to indicate how aware they are of each sensation on a Likert scale, with responses ranging from "Never" to "Always". Higher scores indicate higher subjective awareness of bodily sensations.

2.5.3.6 Brief Sensory Screener. Following the qualitative and experimental research stages of this thesis suggesting the possible salience of sensory difficulties in treating autistic people with AN, a brief sensory screening questionnaire was developed for use in ED services. For each of the five basic senses, participants are presented with a scale and asked to rate their perceived sensitivity. The scale ranges from 0 (low sensitivity) to 10 (high sensitivity), with a score of 5 representing "no differences". Following feedback from clinicians and patients, the "touch" modality was divided into a touch scale (representing non-food sensations) and a texture scale (representing food sensations). The development and evaluation of this screener is detailed in Chapter 13.

2.6 General Procedure

2.6.1 Qualitative Studies

Clinicians (Chapters 3 and 5) were recruited from staff working in the outpatient and day care departments of the South London and Maudsley (SLAM) NHS Foundation Trust National ED Service. Clinicians were invited to take part in an interview assessing their views on treating minority ED groups by email, and presented with an information sheet about the study. Interviews were conducted at their place of work. Written informed consent was obtained prior to interviews starting. Recruitment continued until authors judged that data saturation had been reached as no new information was emerging from the interviews. A total of 10 clinicians took part in the interviews, representing 55% of the total number of clinicians working in the department. One clinician declined to be interviewed about treating autistic people with AN without giving a reason, therefore the sample in Chapter 5 consists of 9 participants.

Men with current or previous experience of ED treatment (Chapter 4) and people with AN on the autism spectrum with current/previous experience of treatment (Chapter 6) were recruited from patients receiving treatment within the SLAM NHS Foundation Trust National ED Service, and Derbyshire Healthcare NHS Foundation Trust. Patients were referred to the study by their treating clinician. Both studies were additionally advertised online on Twitter using the researcher's account. Autistic people (Chapter 8) were recruited through a separate online study on autism and eating

problems, which invited autistic people, people with experience of EDs, and neurotypical controls with no experience of EDs to participate. This study was also advertised on Twitter through personal investigator and departmental accounts. Autistic participants who completed this study and registered an interest in participating in further research were invited to participate in interviews about their experiences of eating as an autistic adult. This included a mix of autistic people with no ED history, and autistic people with experience of an ED. Carers of autistic people with AN were invited through adverts on social media, from contact with the study site through previous research, and through principle investigator contacts.

Participants in these groups (patients, carers, and autistic people) were provided with an information sheet about the study, and written informed consent was obtained prior to interviews starting. Participants were allowed to choose the interview method, including face-to-face at their place of treatment, over the phone, over Skype, or over instant messenger (offered to autistic participants with communication difficulties). Recruitment continued until authors judged that data saturation had been reached as no new information was emerging from the interviews. The final study samples consisted of 14 men (Chapter 4), 13 people with a diagnosis of autism or high autistic traits (Chapter 6), 10 carers (Chapter 7), and 12 autistic people (Chapter 8).

Interviews with participants from all groups were audio-recorded, and subsequently transcribed by the researcher for analysis.

2.6.2 Case-Control Studies

Participants with AN for the case-control chapters (Chapters 11and 12) were recruited into a single sensory study over a period of 10 months from the SLAM NHS Foundation Trust National ED Service. Participants with AN were also recruited by advertising online with Beat, a UK ED charity. HC were recruited by advertising through King's College London, and using the research advert website www.callforparticipants.com. Participants were invited to take part in research on sensory processing in AN, and the relationship to autistic traits, and provided with an information sheet about the study. After giving written informed consent, they completed interoceptive, smell and taste testing (in that order) in a single session lasting up to one and a half hours. This session took place within the university department, or at the participant's place of treatment if they were currently receiving inpatient treatment. People with AN additionally completed the ADOS at the beginning of the session, taking up to one hour. This was video recorded for scoring purposes.

In total, 40 HC and 40 people with AN participated in the sensory testing. Some participants did not complete all measures necessary for inclusion in the interoception analyses (either due to not

completing the interoceptive self-rating measure, or due to environmental noise on the day of testing preventing the administration of the heartbeat tracking task). The final samples for each set of analyses were 40 HC and 40 people with AN in the taste and smell analysis (Chapter 11), and 37 HC and 37 people with AN in the interoception analysis (Chapter 12).

2.6.3 Cross-Sectional Study

Patients accessing treatment for AN in the SLAM NHS Foundation Trust National ED Service were recruited over a period of 3 months. All patients admitted to the inpatient and day patient service were asked to complete the sensory screener in addition to the standard audit questionnaire pack. In the outpatient service, clinicians were encouraged to complete the sensory screener with patients who they felt could benefit from sensory assessment. Any outpatients referred by clinicians to the ED service's specialist autism pathway were also asked to complete the screener. In total 47 patients completed all measures and were included in the study sample.

2.7 Analysis

2.7.1 Qualitative Analysis

Thematic analysis was used for all of the qualitative studies. The approach used in all of these studies, with the exception of Chapter 3, reflects thematic analysis as outlined by Braun & Clarke (2005), and is detailed in each of the individual chapters. Even within this approach, thematic analysis is a flexible method which involves a number of choices and assumptions on the part of the researcher (Braun & Clarke, 2005). This section outlines those decisions. Table 3 summarises the six steps of thematic analysis recommended by Braun & Clarke, with notes on the how these steps were implemented in the current thesis where appropriate.

Table 3

Summary of Braun & Clarke's phased approach to thematic analysis, with notes on exact methods used in the thesis. Adapted from Braun & Clarke (2005).

Phase	Description	Notes on current thesis
Familiarising yourself with the data	Transcription, reading and re-reading, noting initial ideas	All data transcribed by EK, with the exception of carer views on autism and AN (Chapter 7) which were transcribed by a transcription service.
Generating initial codes	Coding interesting features of the data in a systematic fashion, collating data for each code	Codes based on data viewed as relevant to research question. Coding done using NVivo software by EK, and JA in Chapter 7.
Searching for themes	Collating codes into potential themes, gathering data relevant to each theme	Theme identification based on relevance to research question. Themes discussed by all authors.
Reviewing themes	Checking if themes reflect the dataset, generating a thematic map	Themes discussed by all authors

Defining and naming themes	Ongoing analysis to refine themes and the story of the analysis. Creating clear names and definitions for themes.	Themes discussed by all authors
Producing the report	Selection of extract quotes, analysing quotes, relating analysis to previous literature	

The thematic analyses in this thesis were grounded in a realist approach, reporting the experiences and views of participants (Madill, Jordan & Shirley, 2000; Willig, 2013). This assumes that participant descriptions of their experiences are true representations of a knowable world, and that these experiences were influenced by real, material structures (in this case, focusing on healthcare structures). This focus on participant experiences primarily aimed to explore views on what went well in treatment, and what could be improved, rather than the focus on the quality and texture of experiences that typifies more phenomenological approaches.

A deductive approach was taken both to the interview schedules and the analysis: schedules were based on previous research, and subsequent coding and identification of themes reflected patterns of meaning identified in the dataset as relevant to the research aims. A semantic approach was taken to identifying themes: the analysis focused on the explicit, or surface, meanings of the interview data, rather than a more latent approach exploring underlying assumptions or ideologies.

In Chapter 3 (examining clinician views on treatment adaptations for men with EDs), a framework analysis method was used. Framework analysis is a sub-type of thematic analysis and so is very similar to the procedure described above, and was applied in this study with only subtle differences compared to the approach taken elsewhere in the thesis (Gale, et al., 2013). Framework analysis was chosen for this specific chapter as the study was carried out as part of a wider health policy project investigating existing service provision for men with EDs. Framework analysis was originally developed for use in this kind of health policy research (Ritchie & Spencer, 1994). Its systematic approach means that multiple authors can contribute to the coding and interpretation stage without all team members requiring training in qualitative methods, which was important for this project as not all authors had qualitative experience (Gale, et al., 2013). Similarly to the thematic analysis procedure described in Table 3, framework analysis begins with a familiarisation stage (Gale et al., 2013; Srivastava & Thomson, 2009). The coding stage is slightly different: all authors meet before

coding to agree on a coding framework consisting of individual codes which are grouped into defined categories. In this study categories were developed deductively based on the research questions and then refined inductively based on transcript content. Standard thematic analysis uses individual codes only and does not categorise at this stage. In framework analysis, data is then coded and then categorised in charts according to the coding framework. In the final stage, the categorised data is analysed and interpreted. The difference in this approach compared to the standard thematic analysis is that in the standard analysis, individual codes are analysed and interpreted. In framework analysis these codes have already been refined into categories at the framework development stage, and it is these categories which are analysed and interpreted to generate themes. In this way the framework-based thematic approach used in Chapter 3 is very similar to the standard thematic approach taken elsewhere in the thesis, with the exception that there is more of an emphasis on the centrality of the coding framework in analysis.

2.7.2 Statistical Analysis

Outcomes in Chapters 11-13 were evaluated using statistical analyses in STATA software, with more details for each study presented in each chapter. In all studies, variable distributions were first assessed for normality. Parametric tests were used for normally distributed data. Non-normally distributed data was transformed and analysed using parametric tests. Where data could not be transformed, analyses used non-parametric approaches.

In Chapters 11-12 (sensory sensitivity case-control studies), the AN and HC groups were compared using *t*-tests or Mann Whitney U tests as appropriate. Regression analyses were used to assess the contribution of autistic traits to sensory outcomes within the AN group only. The role of autistic traits was assessed relative to anxiety and depression in the taste/smell study (Chapter 11), and relative to alexithymia, anxiety and depression in the interoception study (Chapter 12).

In Chapter 13 (sensory screener pilot), participants with AN were divided into a Low Autistic Traits (LAT) and High Autistic Traits (HAT) group according to scores on the AQ-10. Sensory outcomes for these groups were then compared using *t*-tests. Regression analyses were performed to assess the contribution of autistic traits to sensory outcomes across the sample, relative to anxiety and depression.

Chapter 3: Clinicians' views on treatment adaptations for men with eating disorders: a qualitative study

Kinnaird, E. & Norton, C., Tchanturia, K. (2018). Clinicians' views on treatment adaptations for men with eating disorders: a qualitative study. *BMJ Open, 8*. doi:10.1136/bmjopen-2018-021934

BMJ Open

Clinicians' views on treatment adaptations for men with eating disorders: a qualitative study

Emma Kinnaird,[1] Caroline Norton,[2] Kate Tchanturia[1,2,3]

To cite: Kinnaird E, Norton C, Tchanturia K. Clinicians' views on treatment adaptations for men with eating disorders: a qualitative study. *BMJ Open* 2018;**8**:e021934. doi:10.1136/bmjopen-2018-021934

► Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2018-021934).

EK and CN are joint first authors

Received 27 January 2018
Revised 18 April 2018
Accepted 31 May 2018

[1]Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
[2]Eating Disorders National Service, South London and Maudsley NHS Foundation Trust, London, UK
[3]Department of Arts and Sciences, Ilia State University, Tbilisi, Georgia

Correspondence to
Dr Kate Tchanturia;
kate.tchanturia@kcl.ac.uk

ABSTRACT

Objectives Despite traditional views of eating disorders as a female illness, there is a growing body of evidence that the incidence rate of eating disorders in men is rising. Research suggests that these men may experience unique symptoms and difficulties, however, it is unclear how these unique needs may impact treatment. The aim of this study was to explore clinicians' views on whether men have gender-specific treatment needs, and how far these needs require treatment adaptations.

Design Qualitative interview study using framework analysis to explore the experiences of clinicians working with men with eating disorders.

Setting Outpatient National Health Service eating disorder service in London.

Participants Ten clinicians from a variety of clinical backgrounds participated in the study.

Results The following three themes emerged: male-specific issues identified by clinicians, treatment approaches used for this population and the importance of creating a male-friendly environment. Male-specific issues identified by participants included an increased focus on muscularity and difficulty expressing or discussing emotion. Clinicians also suggested that men may be more likely to adopt a performance-based approach to. This was linked by clinicians to the impact of cultural perceptions of masculinity on their patients. Clinicians in this study felt that these individual needs could be met by adapting existing approaches within a supportive, male-friendly environment. However, there was not consensus over specific adaptations, including identifying risk, the need for male-only groups, or whether male patients needed access to male clinicians.

Conclusions Although men do present with specific treatment needs, these can typically be met within the framework of typical treatment approaches by experienced clinicians in an environment sensitive to the presence of men in an otherwise female-dominated space. However, there are a lack of explicit guidelines for this process, and areas such as male-only treatment spaces require further research.

Strengths and limitations of this study

- ► Exploration of clinician views on an under-researched and increasingly relevant area. Only included clinicians from a London National Health Service service so may not be generalisable to other jurisdictions in the UK and beyond.
- ► Only interviewed clinicians working in a mixed gender eating disorder service, so clinicians may not have had experience of working in a male-only treatment centre.
- ► Raises concepts that can be explored using further empirical research.

INTRODUCTION

Eating disorders (EDs) have traditionally been perceived as an illness affecting young women. However, there has been a significant increase in research interest in men with EDs since studies began to suggest that men, far from being a diagnostic rarity, potentially accounted for up to 10% of individuals with EDs.[1] More recent research suggests that men could represent as many as one in five people with EDs in the UK, with this number rising to one in four people with EDs in the USA.[2 3] With incidence rates of EDs in men rising, effectively treating men with EDs is becoming a growing priority.[4]

There has been an increased recognition of unique symptoms and issues experienced by men with EDs that may translate into unique treatment needs.[5] Men with EDs typically have a later age of onset than women, are more likely to report a previous history of being overweight or obese and are more likely to present with psychiatric comorbidities, including substance abuse, psychosis or personality disorder.[6 7] Moreover, men with EDs appear to experience different symptoms to women likely moderated by sociocultural factors surrounding masculinity and body image.[8] These include less of a desire to lose weight, a greater focus on exercise rather than vomiting or laxatives as a form of purging and specific sexual difficulties.[9–12] Differences in symptoms appear to be influenced by a greater drive towards muscularity in men, compared with a drive for thinness.[13–15] In addition, men with EDs may pose additional physical risks, with the

severity of physical symptoms at the time of treatment presentation potentially heightened due to delays in accessing treatment.[16] Research suggests that using body weight as an indicator of severity and medical risk may be less reliable in male patients, with men potentially exhibiting a higher body weight than their female counterparts, yet also being at greater risk for osteoporosis and bone disease.[17 18] However, at present, no specific clinical guidelines exist for the physical assessment of men with EDs.[5]

The issue of whether men require gender-specific treatment adaptations remains controversial: men with EDs themselves indicate that they may experience different issues to women in treatment,[19] and previous research has suggested gender-specific treatment adaptations to aid recovery in male patients, including male-only groups.[11] In particular, a survey carried out on service provision for men with EDs in Australia raised a number of adaptations used by practitioners, including the importance of challenging masculinity, the possibility of male-only groups and differences in emotion processing.[20] By comparison, other studies have reported that male ED recovery experiences and requirements are highly similar to those of women, with men in fact more likely to achieve better treatment outcomes than women, indicating that treatment adaptations may not be necessary.[21–23] Therefore, there is a significant lack of consensus in this area, with previous qualitative research examining the views of men themselves similarly finding disagreement on whether their gender should be considered as a relevant factor in treatment.[24]

Effectively treating male EDs is becoming a growing priority in the National Health Service (NHS), with the Joint Commissioning Panel for Mental Health recommending that 'gender appropriate services should be available to all.'[25 26] However, the question of what exactly gender appropriate services represent is still uncertain: when men do access treatment in the UK, it is unclear how far current approaches used by clinicians require adaptation for this population. While previous literature has reflected on the need male treatment adaptations, these have not been empirically explored and rather represent clinical recommendations.[27] Consequently, this paper aimed to explore this area by focusing on the following research questions:

1. Do clinicians believe that men with EDs have gender-specific issues?
2. Do clinicians believe that men with EDs require gender-specific treatment adaptations?

METHODS

Design

This study used a qualitative design, employing semistructured interviews exploring the potential of developing treatment adaptations for male EDs. The study is reported according to Consolidated Criteria for Reporting Qualitative Research guidelines.[28]

Setting

Clinicians were recruited from the South London and Maudsley NHS Foundation Trust National Eating Disorders Service. At the time of interviews (January to February 2017), the service had a total of 491 patients, of which 58 (12%) were male.

Participants

The sample consisted of clinicians currently working within the outpatient and day-care teams treating adults with EDs, with a minimum 3 years of experience in this area. Clinicians all had experience of treating male EDs. Clinicians were invited to take part in an interview assessing their views on treating male EDs through email. All individuals agreed to participate, representing 55% of the clinicians in the department and so formed the final cohort. Participants came from a range of clinical backgrounds. All participants were female, reflecting the all-female staff demography of clinicians within the department. Participants were informed that the interviews were part of a project aimed at improving service provision for men with EDs.

Data collection

All interviews took place at the clinician's place of work. Interviews were carried out by CN, the female team leader of the outpatient unit with a background in nursing and EDs. While the impact of participants being interviewed by a senior staff member was a concern for the research team, steps were taken to minimise this as an issue: interviews were held in a room in the hospital separate from the department, and CN discussed the study with participants prior to the actual interview. Moreover, it was emphasised that this was a service improvement project, with an emphasis on service provision rather than assessing the participants as individuals. Written consent was acquired prior to interviews, including consent to audio record. Participants were asked the following questions:

1. Do you work differently with men and women with EDs?
2. When treating men, do you look for any male-specific issues during treatment?
3. What do you think our strengths are in our service treating men with EDs?
4. What do you think could be improved?

The interviewer then asked follow up questions based on themes that arose during the interviews, and anticipated themes based on previous research literature. Interviews lasted between 20 and 40 min, and were audio recorded. Field notes were additionally made during the interview by EK. Recordings were then transcribed with any identifying information removed at the point of transcription. Transcripts were not returned to participants. Following the interviews with the 10 participants who had first agreed to participate, it was judged by the authors that data saturation had been reached as no new information was seen to be emerging from the interviews.

Analysis

Data were analysed using framework analysis.[29] Interview data were entered into NVivo V.11 for data management and coding. A coding framework was developed deductively based on the research aims, questions asked during the interviews and previous literature. The coding framework was then further inductively refined based on interview data content. This gave rise to a coding framework consisting of four main categories focusing on male/female symptom differences, male/female treatment differences, need for male treatment adaptations and service improvements. All authors met to achieve consensus on these categories, and this framework was then applied to the data by EK. Coded data were then analysed to identify themes relevant to the research question. Three themes emerged from the analysis following coding: male-specific issues, treatment approaches and creating a male-friendly environment. Themes are reported together with supporting quotes, anonymised using participant numbers.

Patient involvement

The development and design of this study was informed by a patient steering group consisting of men who had received treatment for EDs in the service. The notion that men may require treatment adaptations was initially explored with this group, with their responses leading to the development of the service improvement project. The interview schedule for this study was based on issues raised and explored by this male patient group.

RESULTS

Male-specific issues

Participants described how although symptoms were broadly similar across genders, men sometimes presented with distinct features, including an increased focus on muscularity. There appeared to be a link between the perceived emphasis of these male patients on exercise and fitness, and a tendency to perceive their illness in more 'mechanical' or functional terms: one participant described how her male patients were more likely to have first made contact with health services due to physical injuries, which led to the diagnosis of an ED, rather than seeking help for emotional distress (participant 2). Where male patients did experience negative emotions, this tended to be perceived as a failure of masculine ideals, rather than in emotional terms.

> Women feel shame and embarrassment with binges and over-eating and all that, men feel less so when they are in company because its more macho to eat more. I don't think they have a problem with that until it feels out of control. (Participant 1)

This was consistent with a common observation across participants that they found it more difficult to encourage their male patients to talk about their emotions compared with female patients. This was again related to the pressures of masculine cultural ideals.

> Only certain emotions are encouraged in men, like it's ok to be angry, it's ok to be tough, you need to be stoic and you're not allowed to be, you know, weak and vulnerable… part of being a man a lot of the time is being able to deal with things and be stoic and just man up and I think actually talking about things isn't always encouraged. (Participant 2)

This raised the concept that for male patients, engaging in ED treatments that require discussing emotions, particularly talking therapy, could itself be seen as a challenge to their masculinity.

A number of clinicians clarified, however, that their observations on male-specific issues were not generalisable to all men, and that symptoms such as an increased focus on muscularity were not necessarily limited to one gender. In particular, the emotional dysregulation symptoms associated with binge eating disorder (BED) were perceived to be similar across both men and women, enabling clinicians to approach treating individuals in a similar way.

> I think I'm doing a lot of the same work with binge eaters, yeah—I think a lot of it is focused on getting them to connect with how they feel. I think that once they've done that there's a major turning point for both females and males. So I don't think that there's anything gender specific that I'm doing with them. (Participant 2)

Consistent with this point, clinicians additionally highlighted that difficulty expressing emotion was not limited to male patients, and in fact was common across patients with anorexia nervosa (AN).

Treatment approaches

Although participants described a number of male-specific issues, the majority of clinicians suggested that they would not fundamentally approach treating men any differently to women. Instead, gender was one of a number of individual factors they considered when approaching treatment.

> I wouldn't necessarily do something different just because the person sitting in front of me was a man or a woman, it's really what they bring and then just using the same models that I use for everybody tailored to the individual rather than the gender or the sexuality or the race. (Participant 4)

From this perspective, they emphasised that a key aspect of therapeutic treatment was that it could be adapted to meet these issues and problems raised by individuals, including gender-specific elements, and suggested that this approach represented a strength of the ED service in treating men.

Consequently, there was a consensus that male needs could be accommodated within the individualised,

flexible nature of normal treatment approaches. Specific adaptations within this treatment framework described by clinicians to meet these specific needs included additional work on education surrounding ED stigma, and a greater focus on emotional expression and identification. In the context of an observed male reluctance to express emotion, or show vulnerability, clinicians suggested that they would proactively raise certain difficulties commonly experienced by men with their male patients, rather than relying on their patients to raise these issues themselves: 'I think at the moment it's about us having to keep asking him questions rather than him being able to come to us' (participant 10).

Therefore, clinicians often perceived a key element of these treatment adaptations as challenging traditional ideas of masculinity. Clinicians felt that men, consistent with motivations behind their symptoms, approached recovery from a mechanical or performance-based perspective which resulted in them attempting to 'eat their way out' of recovery without addressing the underlying emotions, or challenging damaging masculine ideals.

> We could just let him eat his way out, but that's recovery he's done twice before and he's relapsed on both occasions and that's exactly the difference that we were talking about- could this time be different because maybe there's something about, maybe supporting him just to know how to actually ask for help… Because his mum said that on the previous two occasions when he has relapsed it's happened really quickly and he hasn't flagged up that he's having any difficulties. (Participant 10)

Consequently, actively challenging masculine ideals surrounding emotion, vulnerability and performance, was perceived as fundamental to ensuring the success of traditional, emotion focused, treatment approaches for male patients.

The majority of clinicians in this study had extensive experience working with male patients, and felt comfortable and confident in discussing how they adapted treatment for these men, and how they would proactively raise issues that they knew to be particularly relevant to treatment for men with EDs. However, this flexible, informed approach appeared to stem from their previous experience working with men, rather than any previous training. By contrast, a minority of clinicians with less experience working with male patients suggested that they would feel less confident making these kind of treatment adaptations, and indicated a desire for greater training in this area. Additionally, although clinicians were able to discuss the kinds of therapy adaptations they would make when working with men, the majority of participants suggested that they felt less comfortable in managing the physical aspects of male EDs.

> I think that the physical stuff is quite difficult with men. I know less about the physical impacts on men and things like BMI ranges and what I'm looking out for physically with men. I feel more confident knowing the physical, medical side of things with women. (Participant 6)

This to an extent reflected variance in clinical backgrounds across participants, with participants with training in nursing or nutrition exhibiting greater confidence in these clinical aspects of treatment than those with backgrounds in therapy. However, there was disagreement across participants surrounding whether or not male EDs were associated with greater risks. A minority of clinicians suggested that they would be concerned that their male patients were at greater risk from behaviours such as self-harm or suicide, but were unsure how to address this issue in treatment.

Creating a male-friendly environment

Clinicians described the perceived significance of cultural masculine ideals to their male patients, and the impact of these ideals both on treatment needs compared with women, and the way in which men engaged with treatment. From this perspective, clinicians emphasised that rather than fundamentally altering treatment approaches for men with EDs, it was instead important to deliver this treatment within an environment sensitive to the presence of men within a female-dominated service and a female-dominated illness.

Clinicians suggested that EDs and ED treatment were perceived by men (and wider society) as inherently anti-masculine: 'they feel as though it's a female disease' (participant 1). Therefore, they felt that a key element of effectively treating male EDs was the importance of challenging, and not subconsciously reinforcing these perceptions through the process of treatment. This involved raising the issue of wider societal stigma surrounding EDs with their patients, but also acknowledging that this perception of EDs as a female illness was potentially reinforced by the nature of the treatment service: participants were conscious that the service had an all-female staff and a majority of female patients.

> I think it must be very hard for men walking through the door because they are going to be sat in a waiting room full of women, and that's going to be their perception of coming, and then it's played out when they arrive. And also we are a department which doesn't seem to have any male therapists and I am sure all of those things are difficulties. (Participant 3)

Therefore, clinicians described that while normalising male EDs was a key part of treatment, they tried to additionally reinforce this process by adapting the surrounding environment. This included putting up posters in the waiting room about male EDs, and altering therapeutic materials to include both male and female images and body issues.

Within this context of creating an environment supportive of men with EDs, a number of clinicians felt

it was important to create spaces to discuss male-specific issues by recruiting more male clinicians, and introducing male-only treatment groups. However, this was controversial, with participants disagreeing on whether men felt more comfortable discussing male-specific issues with other men. One common reason given by clinicians for creating male-only groups was the perception that their male patients felt awkward because 'women are so much more emotional' (participant 1). However, the perceived benefit of isolating men from this environment contrasts with the beliefs of other clinicians that exposing men to such an environment emphasising emotional expression was key to treatment and recovery.

DISCUSSION

The findings of this study suggest that, from the perspective of the clinicians interviewed, men with EDs do have gender-specific treatment needs. However, these features can potentially be met within the framework of typical treatment approaches by clinicians with an awareness of these needs, in the context of a treatment environment sensitive and supportive to men with EDs.

That clinicians in this study felt that men with EDs were likely to present with a number of specific issues, including an increased focus on muscularity and exercise, is consistent with a large body of previous literature in this area.[8 19] Moreover, the finding of this study that clinicians perceived that these needs can be met by standard treatment approaches reflects previous research suggesting that the symptom differences experienced by men with EDs can nonetheless be accommodated within the same models of ED psychopathology as applied to women—the same models targeted by ED treatments.[30 31] This is consistent with previous research on the views of men with EDs suggesting that men and women experience similar challenges in treatment.[19] Therefore, instead of fundamental changes to ED treatment for males, this study emphasised the importance of clinician openness and empathy in adapting the therapeutic approach to these male-specific issues. This resonates with previous research on the views of men with EDs on treatment, which found that, similarly to women, men highlighted the importance of having an empathetic, non-judgemental therapist to having a positive treatment experience.[32]

This general emphasis on clinician openness and empathy reflects wider therapeutic principles that clinicians should be flexible in adapting therapy to individual needs, even while following manualised treatment programmes.[33] However, the clinicians interviewed in this study highlighted a number of adaptations specifically for men with EDs. Consistent with previous research on treatment adaptations for men with mental health problems, specific recommendations involved including more content on emotional expression and identification.[34] That clinicians particularly highlighted the area of emotional expression as a key gender difference between their male and female patients is in line with a large body of research suggesting that women are typically better at emotion recognition than men, although with significant individual variation across both groups.[35 36]

The concept of challenging ideas of masculinity has previously been identified by practitioners as a particularly important factor in treating male EDs.[20] However, this present study extended this concept by emphasising that challenging ideas of masculinity involved holistic aspects beyond addressing these issues in therapy, highlighting the importance of the treatment environment itself. Previous research has suggested that men with EDs perceive their illness as inherently feminine, and that practitioners should ensure that treatment is inclusive and relevant to men.[19] The present study went further by suggesting that accepting treatment for EDs, as well as the ED itself, may also be perceived by male patients as inherently antimasculine, creating barriers for men engaging in treatment. This resonates with the accounts of men with EDs who documented feeling ostracised in their treatment spaces by staff members and other patients due to being a man.[32] Therefore, this study emphasises the need to create a male-friendly treatment environment to combat this perception. For example, clinicians in this study highlighted the issue of making environmental aspects such as the waiting room more gender neutral. Moreover, with quantitative research documenting that men with EDs may be more concerned with muscularity than an emphasis on thinness, treatment materials for EDs may require adaptation to include these diverse body image issues.[14 15] Moreover, these materials could be adapted to ensure that they are more gender neutral, such as by including examples and images of men.

However, consistent with previous research, the concept of whether creating a safe and sensitive treatment environment for men involved providing access to male clinicians or male-only groups was controversial.[20] Understanding the perceived need for male-only treatment spaces is significant in the context of Department of Health and Mental Health Act Code of Practice guidance stating that NHS organisations should work towards eliminating mixed-sex accommodation on inpatient units, and that women-only day rooms should be provided on mental health units.[37 38] The current study indicates that gender-segregated treatment spaces, rather than helping patients, may in fact be harmful to the therapeutic process: clinicians felt that mixed-gender spaces, whether this meant a female therapist or mixed-gender groups, encouraged men to express emotion, and were concerned that men would feel inhibited in the company of only other men. Significantly, a male-only treatment space may conflict with the importance of challenging masculine norms also identified in this study, and may inadvertently reinforce male perceptions of being ostracised from ED treatment spaces due to not being female.[32] Future research would benefit from specifically exploring these areas in more detail with male patients and their carers.

A key issue raised in this study was that of the relationship between clinician experience and confidence in treating

male EDs. Previous research has raised the importance of clinicians asking 'the right questions' to 'uncover' information or difficulties in men otherwise highly motivated by cultural factors not to disclose these issues,[20] and documenting that male patients may find it difficult to engage with treatment if they perceive that their needs were not understood by the practitioner.[19 32] However, this study highlighted that clinicians who do not have prior experience may be less confident in adapting treatment for men in this way. A specific area of concern was that of physical risk: the majority of clinicians in this study suggested that they were unclear on whether men with EDs had differing physical risk factors to women, reflecting the lack of clinical guidelines in this area.[5] Therefore, this study suggests that clinicians treating men with EDs should potentially be provided with training or guidelines for male-specific issues as part of a systematic approach to treatment.

Limitations

This study took place in a specific ED service based in London. Therefore, the findings of this study cannot be generalised to ED treatment across the UK. However, the issues raised by the clinicians in this study provide a useful basis for further empirical investigation. In addition, this study interviewed clinicians on their views on male EDs in general, rather than specific ED types: while the clinicians in this study did briefly discuss different ED types, including AN and BED, further research is needed to explore gender differences across EDs. Moreover, the disagreement in this study surrounding whether men prefer to talk to other men highlights another drawback of the sampling approach used: the sample consisted only of female clinicians, speculating about male patient perspectives. This emphasises the need for future research addressing the ideas raised in this study surrounding best clinical practice for male ED patients with male patients themselves. Further empirical research is needed to explore the best treatment for men with EDs, and to evaluate the need for treatment adaptations, in order to create a systematic, empirically validated treatment approach.

Clinical and research recommendations

The findings of this study suggest that there is a need for a systematic approach to treating male EDs, consisting of clear, empirically supported clinical guidelines, and training and support for clinicians who lack experience with this population. Moreover, considerations of best practice for male EDs should include a consideration of the treatment environment. Future research should further explore the concepts of best clinical practice and treatment adaptations, with male patients themselves, with a specific focus on the issues of creating a male-friendly environment, and the need for gender-specific or gender-segregated treatment.

Acknowledgements The authors would like to thank the staff of the SLAM outpatient eating disorders service for their support with this paper, in particular Caroline Lewis for transcribing the interviews. The authors would also like to thank the male patients in the ED service who have contributed to the design of this study.

Contributors EK analysed and interpreted the data, and was a major contributor in writing the manuscript. CN collected the data and aided with study design. KT designed and supervised the study and contributed in write-up. All authors read and approved the final manuscript.

Funding This paper represents independent research, for which CN and KT received funding from the National Institute for Health Research (NIHR) Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London. KT would also like to acknowledge financial support from MRC and MRF Child and young adult Mental health—the underpinning aetiology of self-harm and eating disorders. EK received PhD funding for this project through the Medical Research Council Doctoral Training Partnership (MRC DTP) scheme (MR/N013700/1).

Disclaimer The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Competing interests None declared.

Patient consent Not required.

Ethics approval The study was approved by South London and Maudsley NHS trust governance committee as part of a service improvement project assessing current treatment provision for men with EDs

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The datasets used during the current study are available from the corresponding author on reasonable request.

REFERENCES

1. Andersen AE. *Males with eating disorders*. Routledge: New York & London, 1990.
2. Nicholls DE, Lynn R, Viner RM. Childhood eating disorders: British national surveillance study. *Br J Psychiatry* 2011;198:295–301.
3. Hudson JI, Hiripi E, Pope HG, *et al*. The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biol Psychiatry* 2007;61:348–58.
4. Strother E, Lemberg R, Stanford SC, *et al*. Eating disorders in men: underdiagnosed, undertreated, and misunderstood. *Eat Disord* 2012;20:346–55.
5. Murray SB, Nagata JM, Griffiths S, *et al*. The enigma of male eating disorders: A critical review and synthesis. *Clin Psychol Rev* 2017;57:1–11.
6. Carlat DJ, Camargo CA, Herzog DB. Eating disorders in males: a report on 135 patients. *Am J Psychiatry* 1997;154:1127–32.
7. Striegel-Moore RH, Garvin V, Dohm FA, *et al*. Psychiatric comorbidity of eating disorders in men: a national study of hospitalized veterans. *Int J Eat Disord* 1999;25:399–404.
8. Lavender JM, Brown TA, Murray SB. Men, Muscles, and Eating Disorders: an Overview of Traditional and Muscularity-Oriented Disordered Eating. *Curr Psychiatry Rep* 2017;19:32.
9. Stanford SC, Lemberg R. Measuring eating disorders in men: development of the eating disorder assessment for men (EDAM). *Eat Disord* 2012;20:427–36.
10. Murray SB, Griffiths S, Rieger E, *et al*. A comparison of compulsive exercise in male and female presentations of anorexia nervosa: what is the difference? *Advances in Eating Disorders* 2013;1:65–70.
11. Weltzin TE, Cornella-Carlson T, Fitzpatrick ME, *et al*. Treatment issues and outcomes for males with eating disorders. *Eat Disord* 2012;20:444–59.
12. Darcy AM, Doyle AC, Lock J, *et al*. The eating disorders examination in adolescent males with anorexia nervosa: how does it compare to adolescent females? *Int J Eat Disord* 2012;45:110–4.
13. Murray SB, Griffiths S, Mond JM. Evolving eating disorder psychopathology: conceptualising muscularity-oriented disordered eating. *Br J Psychiatry* 2016;208:414–5.
14. Griffiths S, Murray SB, Touyz S. Extending the masculinity hypothesis: An investigation of gender role conformity, body

dissatisfaction, and disordered eating in young heterosexual men. *Psychol Men Masc* 2015;16:108–14.
15. Murray SB, Rieger E, Hildebrandt T, *et al*. A comparison of eating, exercise, shape, and weight related symptomatology in males with muscle dysmorphia and anorexia nervosa. *Body Image* 2012;9:193–200.
16. Räisänen U, Hunt K. The role of gendered constructions of eating disorders in delayed help-seeking in men: a qualitative interview study. *BMJ Open* 2014;4:e004342.
17. Vo M, Lau J, Rubinstein M. Eating Disorders in Adolescent and Young Adult Males: Presenting Characteristics. *J Adolesc Health* 2016;59:397–400.
18. Mehler PS, Sabel AL, Watson T, *et al*. High risk of osteoporosis in male patients with eating disorders. *Int J Eat Disord* 2008;41:666–72.
19. Robinson KJ, Mountford VA, Sperlinger DJ. Being men with eating disorders: perspectives of male eating disorder service-users. *J Health Psychol* 2013;18:176–86.
20. Dearden A, Mulgrew KE. Service Provision for Men with Eating Issues in Australia: An Analysis of Organisations', Practitioners', and Men's Experiences. *Australian Social Work* 2013;66:590–606.
21. Pettersen G, Wallin K, Björk T. How do males recover from eating disorders? An interview study. *BMJ Open* 2016;6:e010760.
22. Agüera Z, Sánchez I, Granero R, *et al*. Short-Term Treatment Outcomes and Dropout Risk in Men and Women with Eating Disorders. *Eur Eat Disord Rev* 2017;25:293–301.
23. Støving RK, Andries A, Brixen K, *et al*. Gender differences in outcome of eating disorders: a retrospective cohort study. *Psychiatry Res* 2011;186:362–6.
24. Thapliyal P, Hay PJ. Treatment experiences of males with an eating disorder: a systematic review of qualitative studies. *Transl Dev Psychiatry* 2014;2:25552.
25. David M, Hutchinson C. *Men, Boys and Eating Disorders*. Panorama: BBC.
26. Joint Commissioning Panel for Mental Health. *Guidance for commissioners of eating disorder services*. Raffertys: Practical Mental Health Commissioning, 2013.
27. de Beer Z, Wren B. Eating Disorders in Males. In: Fox JR, Goss KP, eds. *Eating and its disorders*. New Jersey: Wiley Online Library, 2012.
28. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
29. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Burgress GR, eds. *Analyzing qualitative data*. London: Routledge, 1994:173–94.
30. Fairburn CG, Cooper Z, Shafran R. Cognitive behaviour therapy for eating disorders: a "transdiagnostic" theory and treatment. *Behav Res Ther* 2003;41:509–28.
31. Murray SB, Rieger E, Karlov L, *et al*. An investigation of the transdiagnostic model of eating disorders in the context of muscle dysmorphia. *Eur Eat Disord Rev* 2013;21:160–4.
32. Thapliyal P, Mitchison D, Hay P. Insights into the Experiences of Treatment for An Eating Disorder in Men: A Qualitative Study of Autobiographies. *Behav Sci* 2017;7:38.
33. Addis ME. Evaluating the Treatment Manual as a Means of Disseminating Empirically Validated Psychotherapies. *Clinical Psychology: Science and Practice* 1997;4:1–11.
34. Cochran SV, Rabinowitz FE. Gender-sensitive recommendations for assessment and treatment of depression in men. *Prof Psychol* 2003;34:132–40.
35. Collignon O, Girard S, Gosselin F, *et al*. Women process multisensory emotion expressions more efficiently than men. *Neuropsychologia* 2010;48:220–5.
36. Wright R, Riedel R, Sechrest L, *et al*. Sex differences in emotion recognition ability: the mediating role of trait emotional awareness. *Motivation and emotion*. Switzerland: Springer, 2017.
37. Beasley C, Flory D. *Eliminating mixed sex accomodation*. London: Department of Health, 2010.
38. Department of Health. *Mental Health Act 1983: Code of Practice*. London: Department of Health, 2015.

Chapter 4: “There’s nothing there for guys”. Do men with eating disorders want treatment adaptations? A qualitative study

Kinnaird, E., Norton, C., Pimblett, C., Stewart, C. & Tchanturia, K. (2019). “There’s nothing there for guys”. Do men with eating disorders want treatment adaptations? A qualitative study. *Eating and Weight Disorders, 24*(5), 845-852. doi: 10.1007/s40519-019-00770-0

Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity
https://doi.org/10.1007/s40519-019-00770-0

ORIGINAL ARTICLE

"There's nothing there for guys". Do men with eating disorders want treatment adaptations? A qualitative study

Emma Kinnaird[1] · Caroline Norton[2] · Caroline Pimblett[2] · Catherine Stewart[1,2] · Kate Tchanturia[1,2,3]

Received: 7 May 2019 / Revised: 12 August 2019 / Accepted: 21 August 2019

Abstract

Purpose Men with eating disorders may experience unique issues compared to their female counterparts, and there is a growing interest in how these differences should be addressed in clinical practice. However, the views of male patients on potential treatment adaptations remain under-explored. The purpose of this study was to explore the experiences of men who have experienced treatment for eating disorders.

Methods Men who had experienced eating disorder treatment were recruited through UK National Health Service eating disorder services and online advertising. 14 participants took part in semi-structured interviews discussing their experiences of treatment, and their views on the need for adaptations. Interviews were analysed using thematic analysis.

Results Three main themes were identified from the analysis: a preference for person-centred, rather than gender-centred treatment, a feeling of being "the odd one out" as men in current treatment environments, and recommendations for treatment adaptations.

Conclusions Participants described wanting to be treated as individuals and not defined by their gender. Whilst existing treatment approaches were mostly felt to achieve this individual focus, the actual treatment setting may inadvertently reinforce a perception of atypicality due to being men in a female-dominated environment. Adaptations may therefore be required to make the treatment environment more male friendly. Clinical recommendations are outlined.

Level of evidence V. Qualitative study.

Keywords Eating disorders · Men's health · Qualitative methods · Treatment · Anorexia · Bulimia · Binge eating

Introduction

Traditionally, eating disorders (EDs) have been perceived as an illness primarily affecting women. Consequently, the majority of research on EDs, including core elements such as symptom presentation, diagnosis, and treatment models, have been developed using research predominantly based on female samples [1]. However, there is now a growing recognition that EDs are not exclusively female illnesses: recent research suggests that men could represent as many as one in five people with EDs in the UK, with this number rising to one in four people with EDs in the US [2, 3].

Consequently, there has been an increase in research exploring male EDs, with a particular focus on symptoms and issues potentially specific to men that may have been overlooked in the previously female-dominated literature [4]. Research suggests that men with EDs are more likely experience a later age of onset [5], are more likely to have previously been overweight [5], and are more likely to exhibit a

This article is part of topical collection on Males and eating and weight disorders.

Electronic supplementary material The online version of this article (https://doi.org/10.1007/s40519-019-00770-0) contains supplementary material, which is available to authorized users.

✉ Kate Tchanturia
Kate.tchanturia@kcl.ac.uk

[1] Section of Eating Disorders, Department of Psychological Medicine, King's College London, Institute of Psychiatry, Psychology and Neuroscience, 103 Denmark Hill, SE5 8AZ, London, UK

[2] South London and Maudsley NHS Foundation Trust, London, UK

[3] Illia State University, Tbilisi, Georgia

Published online: 30 August 2019

range of psychiatric comorbidities compared to their female counterparts [6]. Body image concerns may be more orientated towards attaining a muscular body type, reflective of cultural masculine ideals, rather than thinness [1]. In addition, men with EDs may be affected by stigma surrounding their condition stemming from the perception of EDs as a feminine illness [7]. Consequently, men with EDs may delay seeking help or treatment, potentially presenting to services at a later stage in their illness when their symptoms may be more severe [7, 8]. When men with EDs do seek treatment, there is an additional risk that their symptoms may go unrecognised or undiagnosed by health professionals due to the traditional view that EDs only affect women [7].

However, there has been comparatively less research on the implications of these differences for treatment. Treatment models for EDs have been developed using primarily female samples, with clinical trials sometimes excluding men from participating due to them representing an atypical ED population [4]. Literature on whether standard treatment approaches are as effective in men compared to women is often contradictory, with a recent systematic review finding that current evidence on treatment outcomes in men is too mixed to draw strong conclusions [9]. A number of clinical recommendations have been made for treating men with EDs, including an emphasis on creating a gender-sensitive treatment environment [10, 11], an awareness of the role of testosterone [12], and the potential significance of sexuality [10]. However, these typically represent treatment recommendations based on clinical experience rather than the product of empirical research.

A number of recent studies have begun to address this issue by exploring the treatment experiences of men [13–15]. However, there is a lack of consensus in this research on how far gender is relevant to treatment for male with EDs, with studies highlighting disagreement between their participants. Some participants suggested that they wanted to be treated as individuals, with men and women experiencing more similarities in their EDs and in the recovery process than differences [10, 15, 16]. Others suggested that there were male-specific issues that needed to be addressed by treatment, such as differences in body image and potential social pressures surrounding masculinity [8, 10, 16]. An additional problem raised was the difficulty of feeling ostracised or isolated as a male in a predominantly female space [14, 16].

However, the issue of whether these treatment experiences amount for a need for separate and specific treatment adaptations for men with EDs remains unclear. This question is particularly relevant in the UK: Department of Health and Mental Health Act Code of Practice guidance states that National Health Service (NHS) organisations should work towards eliminating mixed-gender accommodation on inpatient units and that women-only day rooms should be provided in mental health units [17, 18]. A recent study on the impact of this legislation found that a majority of both male and female patients felt that mixed-gender units were in fact beneficial to their recovery, with concerns that single-gender accommodation could disadvantage men [19]. To date, two qualitative studies have specifically explored the area of treatment adaptations for men with EDs, and similarly suggest that male-segregated services may not be necessary or beneficial [8, 20]. Rather than suggesting a need for segregated treatments for men, these studies indicate that current treatments can be adapted to become more inclusive: specific recommendations included clinician education on male-specific issues, and the importance of making the service "male friendly", rather than necessarily gender segregated [8, 20]. However, only one of these studies interviewed male patients, and featured a small sample size ($n=5$, Dearden and Mulgrew, 2013). A recent trial of an assessment and treatment track adapted for men, including the provision of male-specific information resources, and a focus on normalizing male experiences of EDs, found that the ED service subsequently received more referrals for men and higher treatment engagement [21].

Therefore, there is a clear need to further explore whether men with EDs would benefit from treatment modifications. Particularly, there is a need to evaluate in more detail suggestions from past research and previous clinical recommendations, including the helpfulness of male clinicians for male patients, male-only groups, and male-specific treatment materials. Consequently, this study aimed to explore the following research question: do men who have experienced ED treatment feel there is a need for gender-specific treatment adaptations?

Methods

Sample

Participants were recruited through collaboration with participating NHS organisations across England, and using online advertising through social media (Twitter). Inclusion criteria were men aged over 18 who had ever received treatment for any kind of ED. Exclusion criteria were not speaking a sufficient level of English for the interviews. Participants were invited, either through online advertising or by their treating clinician, to participate in an interview about their experiences of receiving ED treatment as a man, and their views on what could be improved. Participants then either directly contacted the researcher, or were referred to the study by their treating clinician and invited by the researcher. A total of 19 men were invited or self-referred to participate in the study. Five men (26%) either did not respond to the invitation following clinician referral or declined to participate without giving a reason, leaving a

final study sample of 14 participants (74%). All participants gave written informed consent.

The final sample consisted of 14 men who were currently receiving or had received treatment for an ED across NHS services in England. Seven participants (50% of the sample) had been diagnosed with AN, four (29%) with BN, two (14%) with BED, and one (7%) with EDNOS. Mean age was 29.43 years (SD=8.55), and mean illness length was 8.18 years (SD=6.24). Nine participants (64%) reported other comorbidities in addition to their ED: the most common comorbidity was depression (seven participants, 50%), followed by anxiety (three participants, 21%). Comorbidities experienced by only one participant were obsessive compulsive disorder (OCD), personality disorder, autism, and attention deficit hyperactivity disorder (ADHD).

Six participants (43%) were currently in treatment, while eight (57%) had previously received ED treatment. One participant's ED was treated by their general practitioner (GP) in primary care only, and all the other participants had received referrals to specialist services. Of these 13 participants, 8 participants (62%) received individual therapy only, 1 participant (7%) received group therapy only, and 4 participants (31%) received both group and individual therapy. Two of these participants (16%) received both group and individual therapy in the context of inpatient treatment, while all other participants were treated as outpatients.

Data collection

The study received ethical approval from London City and East Research Ethics Committee and South London (18/LO/0050). Participants were interviewed using a semi-structured interview schedule (supplementary material). These questions were based on previous literature in this area, including specific questions on previous recommendations, such as male-only groups or access to a male therapist. The interview first explored their experiences of treatment in general. Subsequently, participants were asked their views on receiving treatment specifically as a man with an ED, and whether ED treatments need to be adapted for male patients. Participants continued to be recruited into the study until a range of different ED diagnoses were included in the sample, and thematic saturation was identified as being reached by authors EK, CN and KT after new themes ceased to emerge.

EK conducted the interviews either at the participant's place of treatment or over the phone. Interviews lasted between 15 and 30 min and were audio-taped and subsequently transcribed. Any identifying information was removed at the point of transcription.

Data analysis

Data were analysed using thematic analysis [22]. A thematic approach was chosen as this is a flexible type of qualitative analysis not rooted in any specific theoretical framework. Thematic analysis' focus on the interview material itself, rather than its relation to an external theory or model, was felt to align with this study's aim of reporting the experiences and opinions of participants. Transcripts were read and reread by authors EK and KT to ensure familiarisation. An initial set of codes were produced deductively based on the final interview schedule and applied to the data using NVivo 11 software. A deductive approach was chosen with the goal of relating the findings of this study to the previous research in this area which had informed the development of the interview schedule. Following coding, data under each code were exported into a separate Microsoft Word document. EK then analysed the coded data to identify common potential themes and subthemes across codes. Potential themes were then reviewed by authors EK and KT to evaluate if they reflected the original data set.

Results

Three key themes were identified: "Person focused" treatment, "The odd one out", and recommendations for adaptations. Recommendations for adaptations are presented with three subthemes: treatment materials, treatment groups, and access to male staff.

"Person focused" treatment

There was a strong feeling in the sample that men do not require fundamentally different treatment approaches compared to women, and that they viewed current treatment models as applying to their experiences of EDs. Where participants did experience differences relating to their gender, this was in line with current models of EDs. For example, the most common difference between men and women raised by participants was that of body image. Participants who raised this issue did still experience body image difficulties, but experienced them differently to women (such as a focus on muscularity rather than on thinness). Consequently, participants felt that these differences could still be addressed by current treatment approaches:

> "The basics of treatment are the same. It's just tweaking it here and there."—Participant 9.

When asked about treatment problems and what could be improved in the future, participant responses were generally not gender specific, for example, feeling that treatment was in an inconvenient location, or a lack of support following

discharge. The belief that men do not require distinct treatment approaches was closely related to a common theme among participants: they did not want to be treated differently because they were men, but wanted to be seen as an individual:

> "I would say that probably more than gender focused, it should be something person focused… I'm sure gender is important, but I don't think it's the key factor for how a person will feel"—Participant 14.

There was a preference in the sample for individual-focused treatment: from this perspective, gender was viewed as just one of a number of factors which might affect an individual's experience. Participants experienced treatment positively when they felt listened to as individuals, and where they felt that programmes were flexible around their specific needs.

There were concerns that focusing treatment on gender may in fact take away from this kind of individualised approach. First, participants highlighted that different men may experience their gender as more or less relevant to their illness, and that focusing on gender in treatment risks alienating men who do not experience gender-related difficulties. Second, there were concerns that having separate treatments for men risked reducing patients to their gender rather than focusing on their individual needs:

> "I think there's also quite a case to be made for just, sort of treating men the same. The term "stigma" is bandied around so much and I understand why, but I also think that there's sometimes trying to be too careful can be re-stigmatising."—Participant 2.

"The odd one out"

Although participants did not feel that ED treatments themselves need to be altered due to their gender, they did highlight problems with the treatment environment. There was a strong feeling that current treatment environments risk creating a feeling of difference or atypicality due to being men in a female-dominated setting. As men, participants represented a minority in their treatment settings—both as being one of the few male patients, and also being in settings dominated by a mostly female staff. For some participants, this led to feelings of self-consciousness due to their gender, but at the extreme it resulted in negative self-reflection as a man with an ED:

> "There were rows and rows of 18, 19 year old skinny girls, and there was one fat middle aged bloke sitting there. I just felt really uncomfortable with the whole thing really… I've now found out that, I don't think it's a particularly common thing, but there are more middle aged men like me around. But certainly at the time it made me feel like even more of a freak than I was already feeling inside. made me feel like even more of a freak than I was already feeling inside."—Participant 13.

As well as being surrounded by female patients and staff, participants also described how the physical treatment space itself reflected this female dominance:

> "Again, it's all very much directed at women. It's all poetry and birds and lovely which is great, wonderful, but there's nothing there for guys"—Participant 8.

The perception of difference was particularly heightened for the two participants who had experienced inpatient treatment for AN. For one, this difference resulted in a feeling of exclusion due to his gender: as the inpatient unit was a single sex ward, with no local services able to provide a male inpatient bed, he was treated on the inpatient programme but had to go home each night:

> "Obviously I understand why they have single sex wards and stuff but I do think like, you know, it makes you feel like the odd one out"—Participant 12.

Recommendations for adaptations

In the context of these findings, participants did not suggest that they wanted fundamentally different or separate approaches to ED treatment, rather, they voiced a preference for adaptations that would make the treatment environment less female dominated, and more inclusive of men. Participants highlighted specific areas which were felt to be contributing to these feelings of difference, and how they could be improved. These areas are outlined in the following subthemes: treatment materials, treatment groups, and male clinicians.

Treatment materials

The perception of a female-dominated environment was felt to be reinforced by the treatment materials used:

> "The book is, I think, structured around women…for me it was difficult to come at it as a male. This is more likely to attach to women than males."—Participant 4.

Where male examples were included, participants frequently described that this was in a distinct "male" chapter or section, often focused on muscularity, with no other male examples throughout the text. This contributed to their feeling of separation and atypicality, with the materials reinforcing the idea that female EDs were the norm, and male EDs were separate. Instead, participants wanted treatment literature to be more "gender neutral", describing the current lack of male-related examples as rendering men "kind of

invisible" (Participant 9). Rather than separate chapters or leaflets on male EDs, participants wanted male experiences and examples to be more effectively integrated.

> "I would like [treatment materials] to address gender in slightly different ways. Instead of having a chapter on gender and body image, I mean I understand all that and I think it's important, but I would simply like to have in the rest of the material examples that take into account men of all sorts."—(Participant 5).

In addition to examples, participants wanted topics and recommendations to be less female orientated: one participant described feeling alienated by suggested activities which he perceived as feminine, such as drawing pictures, building collages, or taking a bath and lighting candles to alleviate stress (Participant 8). Similarly, men observed that therapeutic materials did not always take into account that men may experience different body image concerns, or different dietary requirements.

Treatment groups

All participants who attended treatment groups described often being the only man, or being in a gender minority in an otherwise female-dominated group. However, experiences of being the minority in these groups varied across participants. Two participants described attending groups for AN, and felt that the experiences discussed were specific to women. This resulted in a feeling of alienation:

> "A lot of the body image work was tailored towards women, which I kind of struggled to kind of engage with. Obviously because I didn't kind of know how they felt about their bodies, and I felt quite differently about mine. Even though there were similarities. So kind of discussions about that in groups I found quite difficult."—Participant 9.

In contrast to the men with AN, one participant with BED who had attended group therapy with predominantly other women with BED felt that the topics covered in his group treatment were not gender specific. He felt that his experiences with his ED were similar to those of women, and found the chance to discuss these common experiences in a group setting beneficial:

> "The main positive was the chance to interact with other people with similar symptoms and also similar experiences… I was actually surprised by how little [being in a female majority group] affected me during the therapy"—Participant 5.

There was similar ambivalence in the sample on their views on whether male patients should have access to male-only groups. The majority of participants suggested that they viewed male-only groups as an important treatment option to have, whilst indicating that they themselves preferred mixed-gender groups. This reflected the feeling of participants that their gender was not determinative of their ED experience, and that they felt that access to a wider range of opinions would be more helpful:

> "Because then you've got a wider range of people's thoughts on everything. And seeing as there are different perceptions that people with eating disorders- that women have, that men have, I feel like there would be more helpful if there was a mixed group of people" (Participant 3).

Only one participant suggested that they were averse to accessing a male-only group, suggesting he would have "freaked out" at having to talk to other men about his experiences (Participant 8). However, this directly contrasted with the views of other participants who felt that it might be easier to "open up" to other men (Participant 4), or that being able to talk to other men would allow them to explore a specifically male perspective on their illness:

> "Obviously the pressures you face in society are very different and I think when people do think of eating disorders in men they often think about, obviously it's a massive problem, but they think about bulking up, steroids, stuff like that, the other extreme to like what people traditionally think of as white middle class girl with anorexia. And so I think, if there was a better way for like men to be able to talk to men in similar positions, I think would be nice." (Participant 12).

Access to male staff

Views were similarly mixed on the issue of whether male patients would benefit from having access to male clinicians. The majority of participants had been treated by a female clinician, and did not see the gender of their clinician as a significant factor in that therapeutic relationship:

> "Male or female it didn't matter, I think it was how they were" (Participant 8).

A minority of participants did feel that they would have either liked to have access to a male member of staff, or felt that it was important to have more male clinicians available in general to combat the otherwise female-dominated environment, and normalise having men in the treatment space. One participant suggested that he found it easier to discuss sensitive subjects with a man:

> "One of my health support workers was a male and I actually found the sessions that I had with him really useful. Because I was able to, I don't know, just connect on a different level if that makes sense. And I

wasn't really sure why because I did similar things to him as I did with others but I talked to him about, I don't know, maybe more personal things with him… it would have been useful to have more men around." (Participant 9).

Discussion

This study explored the ED treatment experiences of men, and their views on the need for gender-specific treatment adaptations. The findings reflect previous research suggesting that men accessing ED treatment do not want their gender to become the defining aspect of their treatment: they want to be seen as individuals, rather than men [16]. However, in this context, existing treatment environments were felt to inadvertently reinforce a feeling of difference of atypicality due to gender as they continue to be female-dominated spaces. The analysis indicates that men with EDs could benefit from adaptations to make the treatment environment a more gender-neutral space.

The findings of this current study reinforce previous research suggesting fundamental changes to ED treatment may not be necessary for men, and that any male-specific needs can be met by standard treatment approaches, and through the process of individual formulation [8, 20]. In this study, participants did not report gender-related difficulties with the actual treatment protocols or in the context of individual therapy. This reflects the findings of experimental studies which suggest that, despite symptom differences such as the specific direction of body image concerns, men with EDs nonetheless experience similar models of ED psychopathology as women [23].

Rather than fundamental changes to treatment approaches, the findings of both this study and previous research suggest that the focus should be on creating a male-friendly treatment environment [8, 20]. The experiences of men explored in this study give insight into what male patients themselves perceive as a male-friendly environment. As highlighted in previous research, all participants in this sample experienced being a minority in an otherwise female-dominated service, contributing to feelings of ostracization and difference [8, 14]. That participants often experienced being given information or materials that seemed targeted towards women recalls previous research on this subject that has highlighted the lack of male-specific ED information [7, 8], and previous research suggestions that materials should be adapted to become more inclusive [10, 20]. However, this study highlighted an additional difficulty: where participants had been provided with male-specific information, this was often separated. Often the "general" information on EDs was implicitly female focused, whilst male information was limited to its own separate section. This had the effect of reinforcing the perception of EDs as a female illness, and men representing an atypical and separate group. The experiences of these participants strongly suggest that any adaptations for men, including changing materials, should focus on not only including male examples and information, but effectively integrating this information.

No participant in this current study felt that their gender caused any difficulties in individual therapy. This suggests that for the participants of this study, problems arose in the wider treatment environment, rather than gender representing a significant barrier on an individual treatment basis. However, individual therapy represents an environment where treatment can be more easily tailored to the individual, whereas wider aspects such as the physical treatment setting may present more of a problem. This difference was highlighted by the experiences and views of participants on group therapy. As in previous research, there was a lack of consensus on the significance of gender in group treatment [8, 11, 13, 16, 20]. The majority of participants were happy to attend mixed-gender groups, however, a minority did voice a preference for male-only groups. For participants who had attended mixed-gender group therapy, experiences were more positive when the group content was felt to be inclusive, with problems arising when content was female focused. This did appear to have a relationship to diagnosis, although the small numbers of participants with each diagnosis in this study makes it difficult to generalise these findings. A patient with BED felt that although he was one of the only men in his group, his illness experiences were highly similar to his fellow female patients. By contrast, two patients with AN who also experienced being the only men in their treatment groups experienced this more negatively as they felt that they experienced certain aspects of the illness differently to the other female patients, such as differing physical side effects and body image concerns, in a way that was not addressed by the group provision. This suggests that where mixed groups are provided, potential differences in male and female experiences should be addressed and accommodated in group content and materials. There was a similar divergence in views on having access to a male clinician—again, a majority of participants were happy to talk to a female therapist, whilst a minority would have liked to have the option to have a male therapist.

These findings suggest that these kinds of adaptations may be a valuable option to offer to male patients, but that in general integration in a male-inclusive space, rather than separation due to gender, may be preferred. The experiences of men in this study reflect previous research indicating that gender-integrated treatment environment(s) may be more preferable for some male patients [19, 20] This is significant in the context of current legislation in the UK stating that hospitals should work towards providing single-gender wards [17, 18]. At present, only one study has empirically

investigated a specialised treatment pathway for men with EDs, with a positive impact on treatment engagement: future research should consider further evaluating the impact of gender-inclusive versus gender-segregated treatment environments on outcomes for both male and female patients [21].

Clinical Implications

Recommendations are made based on the experiences of the participants in this study. The findings suggest that men may not require fundamentally different ED treatment approaches, rather, modifications should focus on making the treatment environment more inclusive. This could include providing gender-neutral treatment materials that integrate male examples and experiences throughout rather than providing separate male-only sections. Information on body image, including topics discussed in mixed-group settings, should also be evaluated to make sure potential gender differences body image difficulties are included. For some men, male-only therapy groups to discuss these kinds of male-specific issues may be preferred. Whilst most men are happy to engage with female clinicians and therapists, having more male clinicians in ED services may help make the service less female dominated, and provide a valuable option for any male patients who may prefer a male therapist.

Limitations

The choice of this study to use a semi-structured interview approach, rather than in-depth interviews, may have limited its ability to explore some issues raised by participants in more detail. Although a range of ED diagnoses were included in the sample, the small size limited the ability to compare experiences across different diagnoses. It should also be noted that only men over 18 were interviewed, and the relevance of gender in treatment for adults may differ to those of children and adolescents.

This study only included men who had experienced ED treatment in UK NHS services. That no participant in this study had experienced male-only treatment spaces may reflect a lack of such gender-specific services in the UK, whereas male-only treatment environments or specialised treatment tracks have been described in the research literature in the USA and Canada [11, 21]. Therefore, the preference in this sample for a greater focus on male inclusion within gender-integrated treatments may be influenced by the fact that participants had not experienced gender-segregated treatment. Additionally, the fact that only two participants who had experienced inpatient treatment were included in this study limits its ability to draw conclusions regarding the appropriateness of mixed-gender accommodations on inpatient units.

Conclusions

The participants in this study did not feel like men need fundamentally different ED treatment approaches, and wanted to be seen as individuals rather than being defined by their gender. However, at present, treatment environments are often female dominated, which may lead to men feeling excluded. Treatment spaces for EDs could consider adaptations to make the environment more "male friendly", such as integrating male experiences into treatment materials, and considering the content of group therapies. Future research should further investigate the provision of gender-inclusive versus gender-segregated treatment for EDs and its impact on patient outcomes.

Funding This work was supported by the Medical Research Council Doctoral Training Partnership (MRC DTP) scheme (MR/N013700/1), the MRC and MRF Child and Young Adult Mental Health (MR/R004595/1), and the Health Foundation, an independent charity committed to bringing better health care for people in the UK.

Data availability The datasets generated during and/or analysed during the current study are not publicly available due to participants not giving consent for their transcripts to be shared in the public domain, but transcript extracts are available from the corresponding author on reasonable request.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the London City and East Research Ethics Committee and South London (18/LO/0050), and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

1. Murray SB, Griffiths S, Mond JM (2016) Evolving eating disorder psychopathology: conceptualising muscularity-oriented disordered eating. Br J Psychiatr 208(5):414–415. https://doi.org/10.1192/bjp.bp.115.168427
2. Nicholls DE, Lynn R, Viner RM (2011) Childhood eating disorders: British national surveillance study. Br J Psychiatr 198(4):295–301. https://doi.org/10.1192/bjp.bp.110.081356
3. Hudson JI et al (2007) The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. Biol Psychiatr 61:348–358. https://doi.org/10.1016/j.biopsych.2006.03.040
4. Murray SB et al (2017) The enigma of male eating disorders: a critical review and synthesis. Clin Psychol Rev 57:1–11. https://doi.org/10.1016/j.cpr.2017.08.001
5. Gueguen J et al (2012) Severe anorexia nervosa in men: comparison with severe AN in women and analysis of mortality. Int J Eat Disord 45(4):537–545. https://doi.org/10.1002/eat.20987
6. Carlat DJ, Camargo CA, Herzog DB (1997) Eating disorders in males: a report on 135 patients. Am J Psychiatr 154(8):1127–1132. https://doi.org/10.1176/ajp.154.8.1127
7. Raisanen U, Hunt K (2014) The role of gendered constructions of eating disorders in delayed help-seeking in men: a qualitative interview study. BMJ Open 4(4):e004342. https://doi.org/10.1136/bmjopen-2013-004342
8. Dearden A, Mulgrew KE (2013) Service provision for men with eating issues in australia: an analysis of organisations', practitioners', and men's experiences. Aust Soc Work 66(4):590–606. https://doi.org/10.1080/0312407X.2013.778306
9. Agüera Z et al (2017) Short-term treatment outcomes and dropout risk in men and women with eating disorders. Eur Eat Disord Rev 25(4):293–301. https://doi.org/10.1002/erv.2519
10. De Beer Z, Wren B (2012) Eating disorders in males. In: Fox J, Goss K (eds) Eating and its disorders. Wiley, Somerset, pp 427–441
11. Weltzin TE et al (2012) Treatment issues and outcomes for males with eating disorders. Eat Disord 20(5):444–459. https://doi.org/10.1080/10640266.2012.715527
12. Andersen AE (1990) Males with eating disorders. Routledge, New York
13. Thapliyal P, Hay PJ (2014) Treatment experiences of males with an eating disorder: a systematic review of qualitative studies. Transl Dev Psychiatr. https://doi.org/10.3402/tdp.v2.25552
14. Thapliyal P, Mitchison D, Hay P (2017) Insights into the experiences of treatment for an eating disorder in men: a qualitative study of autobiographies. Behav Sci. https://doi.org/10.3390/bs7020038
15. Pettersen G, Wallin K, Bjork T (2016) How do males recover from eating disorders? An interview study. BMJ Open 6(8):59. https://doi.org/10.1136/bmjopen-2015-010760
16. Robinson KJ, Mountford VA, Sperlinger DJ (2013) Being men with eating disorders: perspectives of male eating disorder service-users. J Health Psychol 18(2):176–186. https://doi.org/10.1177/1359105312440298
17. Department of Health and Social Care (2010) Eliminating mixed sex accommodation in hospitals. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215932/dh_121860.pdf. Accessed 27 Aug 2019
18. Department of Health and Social Care (2015) Mental Health Act 1983: Code of Practice, revised version. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF. Accessed 27 Aug 2019
19. Fukutomi A et al (2018) Men in eating disorder units: a service evaluation survey regarding mixed gender accommodation rules in an eating disorder setting. BJPsych Bull 42(6):258–263. https://doi.org/10.1192/bjb.2018.51
20. Kinnaird E, Norton C, Tchanturia K (2018) Clinicians' views on treatment adaptations for men with eating disorders: a qualitative study. BMJ Open 8(8):99. https://doi.org/10.1136/bmjopen-2018-021934
21. MacNeil BA, Hudson CC, Leung P (2018) It's raining men: descriptive results for engaging men with eating disorders in a specialized male assessment and treatment track (MATT). Eat Weight Disord 23(6):817–824. https://doi.org/10.1007/s40519-018-0586-y
22. Braun V, Clarke V (2006) Using thematic analysis in psychology. Qual Res Psychol 3(2):77–101. https://doi.org/10.1191/1478088706qp063oa
23. Murray SB et al (2013) An investigation of the transdiagnostic model of eating disorders in the context of muscle dysmorphia. Eur Eat Disord Rev 21(2):160–164. https://doi.org/10.1002/erv.2194

Chapter 5: Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study

Kinnaird, E., Norton, C. & Tchanturia, K. (2017). Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study. *BMC Psychiatry, 17*, 292. doi:10.1007/s40519-019-00770-0

Kinnaird et al. BMC Psychiatry (2017) 17:292
DOI 10.1186/s12888-017-1455-3

BMC Psychiatry

RESEARCH ARTICLE Open Access

Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study

Emma Kinnaird[1], Caroline Norton[2] and Kate Tchanturia[1,2,3,4*]

Abstract

Background: Anorexia nervosa (AN) and autism spectrum disorder (ASD) form a relatively common comorbidity, with poorer illness outcomes and poorer responses to treatments for AN compared to individuals without ASD. However, the treatment of this comorbidity remains poorly understood: no research to date has examined how clinicians currently approach treating AN/ASD. This study aimed to explore the experiences of clinicians working with comorbid AN/ASD using qualitative methods in order to identify areas for future improvement.

Methods: Interviews with individual clinicians ($n = 9$) were carried out and explored using thematic analysis.

Results: The findings suggest that many clinicians lack confidence in treating this comorbidity, which requires specific changes to treatment to accommodate the issues raised by comorbid ASD. At present, any adaptations to treatment are based on the previous experience of individual clinicians, rather than representing a systematic approach.

Conclusions: Further research is needed to empirically assess potential treatment modifications for this group and to establish guidelines for best clinical practice.

Keywords: Anorexia nervosa, Autism spectrum disorder, Treatment, Qualitative study, Comorbidity

Background

There has been an upsurge in research over the past few years documenting the relationship between autistic spectrum disorder (ASD) and anorexia nervosa (AN), first identified by Gillberg in 1983 [1]. ASD is a neurodevelopmental disorder characterised by problems in social and communicative functioning and restricted patterns of behaviour with onset in the early developmental period [2]. By contrast, AN is a severe eating disorder, characterised by a low body weight due to restricted energy intake, a fear of gaining weight, and an undue influence of shape and weight on their self-evaluation [2]. Unlike ASD, AN does not typically develop until adolescence or early adulthood [3].

Despite these apparent differences, it has been consistently demonstrated across a number of studies that ASD traits are elevated in some individuals with AN, and that these traits may contribute towards some of the psychopathological features associated with AN [4–7]. Although research in this area is ongoing, it appears that there is a higher prevalence of diagnosed ASD in individuals with AN compared to the healthy population [8–10]. This relationship between the two conditions appears to be underpinned by common underlying neuropsychological and social problems, with individuals with AN exhibiting neurocognitive problems more typically associated with ASD. AN has been associated with significant inefficiencies in theory of mind, cognitive flexibility and central coherence [11–16]. Individuals with AN are also characterised by poor social and emotional functioning [17, 18], including interpersonal problems [19], impaired facial emotion recognition [20, 21], diminished facial emotion expression [22, 23], and social anhedonia [24, 25]. These problems are associated with a longer illness duration, higher illness

* Correspondence: Kate.Tchanturia@kcl.ac.uk
[1]King's College London, London, Institute of Psychiatry, Psychology and Neuroscience, Department of Psychological Medicine, London, UK
[2]Eating Disorders National Service, South London and Maudsley NHS Foundation Trust, London, UK
Full list of author information is available at the end of the article

severity, and poor treatment outcomes [13, 24–27]. Consequently, Treasure & Schmidt (2013) have proposed that these cognitive, socio-emotional and interpersonal problems in fact act as maintaining factors for the disorder itself [28]. It is therefore possible that the presence of underlying ASD traits effectively maintains AN [5, 29].

A key challenge in examining the relationship between AN and ASD is the fact that the starvation, depression and anxiety symptoms present in AN can also contribute to these cognitive and social problems, rather than indicating the presence of an underlying neurodevelopmental disorder [30–32]. However, these difficulties have been found to precede the onset of AN in childhood, and to persist to a less severe extent following weight gain and recovery [13, 18, 27, 31, 33–35]. This suggests that these problems may for some individuals represent underlying traits that preceded the onset of the disorder, rather than symptoms resulting from starvation: a recent case series study identified a number of individuals with AN and ASD traits with longstanding neurodevelopmental difficulties, confirming a genuine overlap in some individuals between the two disorders [9].

Nonetheless, this overlap between potential symptoms of starvation and the possibility of comorbid ASD can make diagnosis difficult if the patient is still in the acute stage of their illness: a longitudinal cohort study on ASD and AN comorbidity found that a number of patients with AN had an ASD diagnosis at one stage of the study, but were then later found to no longer meet the criteria [36]. Consequently, not all psychopathological features seen in individuals with AN that resemble ASD are associated with an underlying neurodevelopmental disorder.

Although only a limited number of patients with AN show ASD traits, understanding the relationship between ASD and AN is crucial because this comorbidity has been related to poorer illness outcomes [29]. Individuals with high ASD traits have been found to respond more poorly to psychological treatments [37], with a clinical case study of two children with comorbid AN and ASD suggesting that the rigidity and low introspection characteristic of ASD hindered responses to traditional therapeutic programmes [38]. Consequently, it has been suggested that individuals with comorbid AN and ASD require adapted or targeted treatment programmes [31, 38]. Treatments such as cognitive behavioural therapy (CBT) have previously been adapted for individuals with ASD and comorbid anxiety or depression [39]. However, there has been no research to date on how clinicians currently approach treating comorbid AN and ASD, and how more typical therapeutic approaches may be adapted for these patients.

This paper presents an exploratory qualitative study of the experiences of clinicians treating comorbid AN and ASD. The aim is to understand how clinicians approach treating comorbid AN and ASD, and how they adapt their typical therapeutic techniques for these patients. This paper will focus on the following research questions:

1. How do clinicians react if their patient presents with AN and comorbid ASD or ASD traits?
2. What specific issues do clinicians face when treating comorbid ASD and AN?
3. What treatment techniques or approaches are effective in treating comorbid ASD and AN?

Methods

Design

The study adopted a qualitative design, using semi-structured interviews to explore therapist experiences of treating people with comorbid AN and ASD. The study was part of a wider clinical service improvement project approved by South London and Maudsley NHS trust governance committee.

Participants

Participants were recruited from the South London and Maudsley NHS Foundation Trust Eating Disorders Service outpatient and daycare departments. Participants were all currently working with the outpatient team treating adults with EDs. Participants were invited prior to data collection through email due to having a minimum of 3 years of clinical experience working with patients with ED. All participants had a prior professional relationship with the interviewer. Ten clinicians were invited to take part, and nine agreed to take part and so formed the final cohort. One clinician did not feel comfortable discussing the interview topic and so was not included in the sample. This study included a range of clinical backgrounds, including nurse therapists, cognitive behavioural therapists, a cognitive analytical therapist, a psychotherapist, a dietician, an occupational therapist. All participants were female.

Data collection

Written informed consent was acquired prior to the interview. The interviews were semi-structured with open ended questions, conducted by CN and recorded by EK. No other individuals were present. CN is a female team leader of the outpatient ED team, with a background in nursing and EDs. Participants were asked one general question: "What do you do if your patient with an eating disorder has an autism spectrum disorder diagnosis or traits?" (Additional file 1). The interviewer then asked follow-up questions about specific themes that emerged in each interview. The average length of each interview was 20 min. No repeat interviews were conducted.

All interviews took place within the outpatient department as the therapist's place of work. Participants were

informed of the study's purpose prior to data collection, and made aware that the study was being conducted due to author interest in improving service provision for individuals with ASD and AN. Interviews were audio recorded and transcribed, with any identifying information removed at the point of transcription. EK additionally made field notes during data collection. Transcript were not returned to participants. Following the nine interviews, it was judged that a point of data saturation had been reached and recruitment ceased.

Data analysis

Data were analysed using a thematic analysis methodology, which aims to identify and summarise relevant patterns in the data [40]. Data were read and re-read in order to achieve familiarity with the data by all authors. Data were then interpreted and coded line by line by the first author (EK) using NVivo 11, deriving themes from the data relevant to the research question. The coding frame at this stage included a focus on therapist perceptions of having a patient with AN/ASD, difficulties treating AN/ASD and therapeutic techniques used. These codes were reviewed and grouped into key themes, summarised in the Results section. All authors met to achieve consensus on the themes. Participants did not give feedback on the findings.

Results

Themes and sub themes identified in the analysis are summarised in Table 1. The number of participants endorsing each item is given to highlight key patterns and ensure the transparency of analysis. Themes with low participant endorsement but high relevance to the research question were retained in the analysis.

Table 1 Summary of themes and sub-themes

Theme	Sub-Theme	Participant endorsement
Therapist reactions to having a patient with ASD	Lack of confidence	1, 2, 3, 4, 6, 7
	Information seeking	2, 4, 5, 7
	Diagnostic referral	2, 4, 5, 8
Specific issues in treating comorbid ASD and AN	Difficulty treating	1, 2, 4
	Communication problems	1, 2, 4, 5, 6, 9
	Emotions	1, 5, 8
	AN/ASD overlap	1, 2, 3, 7, 8
	Sensory	5
Techniques used to treat comorbid ASD/AN	Patient-driven process	1, 2, 4, 7, 8
	Adaptations to therapy	1, 5, 9
	Adaptations to communicative style	2, 6, 9
	Specific modifications	1, 4, 5, 8, 9

Clinician reflections on having a patient with ASD

A common theme throughout the interviews was a lack of clinician confidence or experience in treating patients with comorbid ASD (60% of participants). Consequently, when treating a patient already diagnosed with ASD, clinicians suggested that their first reaction would be to initially look for more information on the subject. As well as looking for resources online or reading books, clinicians described seeking help from other, more experienced/senior members of the treatment team:

> "So, but I don't know a huge amount about ASD so I'd certainly find, speak to somebody that knows a bit more about it or look up something just to think about what I might need to be aware of." – Participant 7.

Where the patient was exhibiting ASD traits but had no prior diagnosis, a number of clinicians suggested that they would refer the individual to a specialist ASD service for the assessment. However, there did not appear to be clear or common pathways for assessment referrals, with participants variously suggesting that they would consult a specialist registrar doctor (Participant 4), the team lead clinical psychologist (Participant 4), specialist services (Participant 5) or carrying out a brief assessment themselves (Participant 5).

Participant 5 also emphasised that she would not do this automatically, but would rather consider a referral on an individual basis:

> "If we're thinking about whether someone who's undiagnosed who may have an ASD diagnosis, I will be- along the course of therapy- thinking about whether it's going to be helpful to pursue that or not. Of course, with some people it's not helpful to even think about diagnosis - it's not going to be something that they're going to gain from it."

Participant 8 also noted that she would wait until the patient was weight restored until she referred for a diagnosis, "because low weight can actually make it seem like they have ASD or ASD traits".

Specific issues in treating comorbid ASD and AN

Clinicians raised a number of issues they had previously encountered when treating patients with comorbid ASD and AN, with Participant 2 noting "it was difficult to work with". A common difference noted by clinicians compared to non-ASD patients was their communication styles:

> "You listen to the way they respond, if you like, and sometimes their responses are very short compared to somebody that doesn't have ASD. You know sometimes, you start somebody off on something and they can roll on for ages telling you about a situation. But I find with autism every time you ask for something you get a sentence back - you don't get, sometimes it's quite curt, you know, almost to the point of rude but not rude because that's how they respond" – Participant 1.

Participant 1 suggested that these communication problems made building a therapeutic relationship more difficult- "it's really hard to get communication going". Clinicians found that they had to adapt their own communication styles to meet the needs of the patient, with Participant 2 describing the need to "speak the same language as her (patient with ASD)". Participant 6 noted the need for "clear and unambiguous instructions", and the need to go into more detail in some cases. Participant 9 similarly highlighted that "I am very careful about the things that I say being taken literally so I might not be thinking about using context humour or metaphors..., I would be keeping it very simple".

Participants also reported that they found that patients with ASD appeared to be "less emotional- like they're more closed off" (Participant 8). As well as appearing less emotional, patients with ASD found it harder to communicate their emotions to the clinician: "they can often have a really poor ability to understand and identify what they're thinking and feeling" (Participant 5). Participant 1 suggested that patients with ASD approached emotional identification from a more logical perspective, if at all: "you hit the emotions and then they draw back, they don't want to know. Or they, not necessarily don't want to know, they put a practical take on it. You know, keep the emotions at a level that they then mentally work through it".

A key problem clinicians raised in treating individuals with comorbid ASD and AN was the difficulty in differentiating between the eating disorder and the ASD, particularly in terms of rigid thinking patterns and routines. Participant 1 noted that the rigidity of ASD made tackling AN symptoms difficult:

> "I think that the problem with eating disorders is the rigidity of it- is that patients tend to hate change, hate anything different, very rigid rules around food. And it sounds like an eating disorder but may not be, but just their [individuals with ASD] rigid rules around things. They might eat the same food every day or have three different foods that they eat and they can't bear to try anything else, they just can't bear it and that's quite hard to shift."

Participant 3 suggested that she would try and judge to what extent the patient's rigidity was due to their AN and could therefore be improved:

> "Because there's an element of overlap between the ASD diagnosis and the rigidity that comes with an eating disorder, it's quite useful, at least in my head, if I can start thinking about what, where there could be some flexibility, and where there probably isn't going to be some flexibility."

Whereas treatment for EDs would typically focus on changing symptoms, Participant 5 highlighted that treating patients with comorbid ASD often entailed a process of acceptance and adaptation for both the patient and the clinician:

> "The other thing is difficulties with rigidity and routine and being realistic about how much flexibility you're going to achieve with these patients. Helping people to live with the fact- in fact, helping people to accept and be ok with the fact that they have that type, have that approach to plans and routines. And that can be really helpful. And working at level of flexibility which is going to give them some movement in their life without asking too much of them."

Only one participant mentioned that individuals with comorbid ASD may have additional sensory problems that might complicate the treatment of their ED:

> "She was really sensory around food and textures and so thinking about really involving the dietician carefully, and prepping the dietician and co-working with the dietician around what they're going to suggest. So it kind of helped around those sorts of things... And then I guess just being mindful of some of the other sensory things is really important as well. I had worked with another patient who found sound and other people very activating for her. And just helping her to manage that and accept that, and to explore ways of managing it which is going to be helpful." (Participant 5).

Techniques used to treat comorbid ASD/AN

Clinicians noted a number of techniques or approaches that they had previously used in treating patients with comorbid ASD/AN. A common theme was that of a patient-driven process, where the clinician would specifically ask the patient what they found helpful:

> "Basically would just ask her along the way, you know like questions checking in with her around, you know,

the work we were doing and whether she thought she was getting stuck with ASD routines and habits, or it was more like her eating disorder that was in play. So kind of like trying to tailor it with her ASD in mind." (Participant 2).

Therapists noted that they would adapt certain aspects of their therapeutic approach:

"And do lots of work around emotional identification and thought identification in session, and at a level that you might do even with young people or teenagers, or younger people and younger children, around that." (Participant 5).

"I would be keeping it very simple, very basic and be doing a lot of work around mentalising as well in a way that I way if someone has got personality disorder or borderline personality disorder". (Participant 9).

Individual participants also noted a range of smaller adaptations that they used within treatment, including involving family members in therapy to help with communication (Participants 4, 5, 8), and maintaining a routine with appointment time and location (Participant 9). Participant 8 noted that she had previously used a range of techniques to help with communication and building a relationship with the patient:

"What I do is that I ask them to write like, like write things before session and then to read it or ask me to read it so that it's easier for them to write it down. I've done sessions where they actually don't look at me. So the chair is turned, and they felt more comfortable talking to alternative objects- so they would bring something like I had a patient with a teddy bear, and she would talk to the teddy bear."

Similarly, Participant 5 had previously used a number of approaches to aid with emotional identification:

"Lots of work around emotional identification and thought identification in session, and at a level that you might do even with young people or teenagers... around that. Like using faces with different emotional expressions on them and using that as a crib sheet that you have in session all the time, and asking them to point to what they're feeling on there. I get them to colour in different colours to help them represent it."

Discussion

Despite literature suggesting that individuals with both AN and ASD have specific treatment needs, at present there has been no research exploring how clinicians treat this clinically significant common comorbidity, with estimated prevalence rates in AN ranging between 23 and 30% [8, 10]. The findings of this study suggest that clinicians face specific challenges in treating patients with comorbid AN and ASD, and that these challenges that may be compounded by a lack of clinician confidence.

The majority of clinicians interviewed suggested that they lacked confidence or experience in treating individuals with comorbid AN and ASD. Whilst the staff team structure of the eating disorder unit enabled clinicians to consult with more experienced colleagues for support in these cases, it may be possible that staff would benefit from a pathway or guide advising on best practice in these cases. Having a developed pathway could also benefit the referral process for clinicians who have patients with suspected ASD but no official diagnosis: firstly, a pre-arranged referral pathway to specialist services could speed up the diagnostic process. In addition, experienced clinicians noted that they would delay referral until the patient was weight restored to ensure that the apparent ASD traits were not as a result of starvation: it may therefore be appropriate to include a minimum BMI threshold in this diagnostic process to protect against misdiagnosis. This association between ASD traits and traits caused by food restriction in AN recognised by experienced clinicians reflects research suggesting that although the prevalence of ASD is higher in AN, these traits may be exaggerated in some cases by the effects of starvation causing a "pseudo- ASD" which resolves with refeeding and weight restoration [32, 41–43].

Clinicians were able to reflect on how they would adapt their approaches to accommodate ASD traits when treating AN. This reflects a strength of the modern therapeutic approach: clinicians are taught to adapt to the specific needs of the patient through a process of formulation [44]. Nonetheless, previous research suggests that patients with comorbid AN and ASD respond less successfully to treatment than their neurotypical counterparts [29, 37]. Issues with treating individuals with AN and ASD raised by the clinicians in this study suggest that treatment may be hindered due to a number of issues, primarily problems with patient/therapist communication and difficulty identifying underlying thoughts and emotions. This provides support previous research speculating that the socio-communicative and emotional profile of ASD may hinder more traditional therapeutic approaches [31]. NICE guidelines recommend that AN is treated using psychological interventions, such as cognitive analytical therapy (CAT) and cognitive behavioural therapy (CBT). However, research has consistently proven that the success of psychological interventions is influenced by the relationship between the therapist and the patient: it is possible that the

socio-communicative difficulties noted by the clinicians in this study hinder this process [45]. Moreover, psychological interventions require the use of metacognition and emotional recognition, which research suggests may be hindered in people with ASD [46, 47].

Previous studies examining treatments for individuals with ASD and psychiatric comorbidities have recommended a range of adaptations to programmes such as CBT, including increasing the number of treatment sessions and introducing materials to aid with emotional identification and communication [39]. In this study, clinicians more experienced in treating individuals with ASD had developed similar techniques to combat these problems, including focused work on emotional identification, the use of materials such as emotional crib sheets, involving family members in treatment, and adapting communicative styles. However, at present the experiences of these clinicians are not shared in specific guidelines or training for other staff members, and sharing of expertise relies on clinical supervision and peer support. With CBT adaptations already existing for ASD and comorbid depression and anxiety, the findings of this present study suggest that therapy for ED also requires the development of specific modifications for an patients with both AN and ASD traits [39, 48].

The strengths of this study lie in its use of well-developed qualitative techniques to evaluate an under-researched topic with clear clinical relevance. The study additionally interviewed participants from a range of clinical backgrounds, giving a range of important perspectives. The use of a semi-structured interview technique allowed the exploration of the topic whilst enabling participants to explore and express their views. However, this study represents a preliminary, qualitative study in the growing area of AN and ASD links that deliberately focused on clinician views and experiences, rather than providing an empirical analysis of the effects of comorbid AN and ASD on treatment. Furthermore, the study took place within a specific London NHS ED Service, and so findings cannot be generalised to all clinicians and services. Further research is needed to empirically evaluate treatment modifications necessary for comorbid AN and ASD, in order to create a standardised, empirically supported treatment approach.

Conclusions

It is clear that individuals with comorbid AN and ASD represent specific treatment challenges to clinicians, and so require specific treatment adaptations [29]. In this study, treatment modifications appear to be the result of individual therapist experience and knowledge, rather than representing a standardised method. A more standardised approach could incorporate the suggestions for treatment recommended by clinicians in this study, thus providing support to clinicians who lack experience in treating this challenging patient group. This approach could take the form of specific guidelines, treatment pathways, or staff training.

Additional file

Additional file 1: Interview guide: summary of interview question. (DOCX 13 kb)

Abbreviations

AN: Anorexia nervosa; ASD: Autism spectrum disorder; BMI: Body mass index; CAT: Cognitive analytical therapy; CBT: Cognitive behavioural therapy; ED: Eating disorder; NICE: National Institute for Health and Clinical Excellence

Acknowledgements

The authors would like to thank outpatient and day care treatment programme therapists for their time and participation in the study. The authors would like to acknowledge the Medical Research Council and Biomedical Research Centre for funding.

Funding

EK received PhD funding for this project through the Medical Research Council Doctoral Training Partnership (MRC DTP) scheme. CN was supported from Biomedical Research Centre (BRC) at SLAM and IoPPN. KT would like to acknowledge financial support from MRC and Medical Research Foundation Child and young adult Mental health – the underpinning aetiology of self - harm and eating disorders. The MRC and BRC had no involvement in any aspect of this study.

Availibility of data and materials

The datasets used during the current study are available from the corresponding author on reasonable request.

Authors' contributions

EK analysed and interpreted the data, and was a major contributor in writing the manuscript. CN collected the data and aided with study design. KT designed, and supervised the study and contributed in write up. All authors read and approved the final manuscript.

Ethics approval and consent to participate

Clinical Improvement project approved by South London and Maudsley NHS trust governance committee. Prospective participants were informed about the study by CN at least a week prior to data collection. Immediately before data collection, CN restated the goals of the study for participants and reviewed the consent form and information sheet. All participants signed a consent form before interviews commenced.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Publisher's Note

Author details

[1]King's College London, London, Institute of Psychiatry, Psychology and Neuroscience, Department of Psychological Medicine, London, UK. [2]Eating Disorders National Service, South London and Maudsley NHS Foundation Trust, London, UK. [3]Ilia State University, Tbilisi, Georgia. [4]POSI, King's College London, IoPPN, Psychological Medicine, 16 De Crespigny Park, London SE5 8AF, UK.

Received: 17 May 2017 Accepted: 3 August 2017
Published online: 16 August 2017

References

1. Gillberg C. Are autism and anorexia nervosa related? Br J Psychiatry. 1983; 142(4):428.
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington: American Psychiatric Publishing; 2013.
3. Volpe U, Tortorella A, Manchia M, Monteleone AM, Albert U, Monteleone P. Eating disorders: what age at onset? Psychiatry Res. 2016;238:225–7.
4. Baron-Cohen S, Jaffa T, Davies S, Auyeung B, Allison C, Wheelwright S. Do girls with anorexia nervosa have elevated autistic traits? Mol Autism. 2013;4:24.
5. Tchanturia K, Smith E, Weineck F, Fidanboylu E, Kern N, Treasure J, Cohen SB. Exploring autistic traits in anorexia: a clinical study. Mol Autism. 2013;4:44.
6. Rhind C, Bonfioli E, Hibbs R, Goddard E, Macdonald P, Gowers S, Schmidt U, Tchanturia K, Micali N, Treasure J. An examination of autism spectrum traits in adolescents with anorexia nervosa and their parents. Mol Autism. 2014;5:56.
7. Huke V, Turk J, Saeidi S, Kent A, Morgan JF. The clinical implications of high levels of autism Spectrum disorder features in anorexia nervosa: a pilot study. Eur Eat Disord Rev. 2014;22(2):116–21.
8. Huke V, Turk J, Saeidi S, Kent A, Morgan JF. Autism Spectrum disorders in eating disorder populations: a systematic review. Eur Eat Disord Rev. 2013; 21(5):345–51.
9. Mandy W, Tchanturia K. Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. Mol Autism. 2015;6:6.
10. Wentz E, Lacey JH, Waller G, Rastam M, Turk J, Gillberg C. Childhood onset neuropsychiatric disorders in adult eating disorder patients - a pilot study. Eur Child Adolesc Psychiatry. 2005;14(8):431–7.
11. Lang K, Lopez C, Stahl D, Tchanturia K, Treasure J. Central coherence in eating disorders: an updated systematic review and meta-analysis. World J Biol Psychiatry. 2014;15(8):586–98.
12. Westwood H, Stahl D, Mandy W, Tchanturia K. The set-shifting profiles of anorexia nervosa and autism spectrum disorder using the Wisconsin card sorting test: a systematic review and meta-analysis. Psychol Med. 2016;46(9): 1809–27.
13. Bora E, Kose S. Meta-analysis of theory of mind in anorexia nervosa and bulimia nervosa: a specific impairment of cognitive perspective taking in anorexia nervosa? Int J Eat Disord. 2016;49(8):739–49.
14. Tchanturia K, Happe F, Godley J, Treasure J, Bara-Carril N, Schmidt U. 'Theory of mind' in anorexia nervosa. Eur Eat Disord Rev. 2004;12(6):361–6.
15. Russell TA, Schmidt U, Doherty L, Young V, Tchanturia K. Aspects of social cognition in anorexia nervosa: affective and cognitive theory of mind. Psychiatry Res. 2009;168(3):181–5.
16. Tchanturia K, Davies H, Roberts M, Harrison A, Nakazato M, Schmidt U, Treasure J, Morris R. Poor cognitive flexibility in eating disorders: examining the evidence using the Wisconsin card sorting task. PLoS One. 2012;7(1): e28331.
17. Oldershaw A, Hambrook D, Stahl D, Tchanturia K, Treasure J, Schmidt U. The socio-emotional processing stream in anorexia nervosa. Neurosci Biobehav Rev. 2011;35(3):970–88.
18. Mette Bentz MS, Moellegaard Jepsen JR, Pedersen T, Bulik CM, Lennart Pedersen MS, Ragsberg AK, Plessen KJ. Impairment of social function in young females with recent-onset anorexia nervosa and recovered individuals. J Adolesc Health. 2017;60:23–32.
19. Westwood H, Lawrence V, Fleming C, Tchanturia K. Exploration of friendship experiences, before and after illness onset in females with anorexia nervosa: a qualitative study. PLoS One. 2016;11(9):e0163528.
20. Cagir-Nazal HP, Corfield F, Cardi V, Ambwani S, Leppanen J, Olabintan O, Deriziotis S, Hadjimichalis A, Scognamiglio P, Eshkevari E, et al. A systematic review and meta-analysis of 'Systems for Social Processes' in eating disorders. Neurosci Biobehav Rev. 2014;42:55–92.
21. Dapelo MM, Bodas S, Morris R, Tchanturia K. Deliberately generated and imitated facial expressions of emotions in people with eating disorders. J Affect Disord. 2016;191:1–7.
22. Lang K, Larsson EEC, Mavromara L, Simic M, Treasure J, Tchanturia K. Diminished facial emotion expression and associated clinical characteristics in anorexia nervosa. Psychiatry Res. 2016;236:165–72.
23. Davies H, Wolz I, Leppanen J, Fernandez-Aranda F, Schmidt U, Tchanturia K. Facial expression to emotional stimuli in non-psychotic disorders: a systematic review and meta-analysis. Neurosci Biobehav Rev. 2016;64:252–71.
24. Tchanturia K, Davies H, Harrison A, Fox JRE, Treasure J, Schmidt U. Altered social hedonic processing in eating disorders. Int J Eat Disord. 2012;45(8): 962–9.
25. Harrison A, Mountford VA, Tchanturia K. Social anhedonia and work and social functioning in the acute and recovered phases of eating disorders. Psychiatry Res. 2014;218(1–2):187–94.
26. Hartmann A, Zeeck A, Barrett MS. Interpersonal problems in eating disorders. Int J Eat Disord. 2010;43(7):619–27.
27. Schulte-Ruther M, Mainz V, Fink GR, Herpertz-Dahlmann B, Konrad K. Theory of mind and the brain in anorexia nervosa: relation to treatment outcome. J Am Acad Child Adolesc Psychiatry. 2012;51(8):832–41.
28. Treasure J, Schmidt U. The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. In: Journal of eating disorders. Vol. 1; 2013.
29. Nielsen S, Anckarsater H, Gillberg C, Rastam M, Wentz E. Effects of autism spectrum disorders on outcome in teenage-onset anorexia nervosa evaluated by the Morgan-Russell outcome assessment schedule: a controlled community-based study. Mol Autism. 2015;6:14.
30. Calderoni S, Fantozzi P, Balboni G, Pagni V, Franzoni E, Apicella F, Narzisi A, Maestro S, Muratori F. The impact of internalizing symptoms on autistic traits in adolescents with restrictive anorexia nervosa. Neuropsychiatr Dis Treat. 2015;11:1175–85.
31. Treasure J. Coherence and other autistic spectrum traits and eating disorders: building from mechanism to treatment. The Birgit Olsson lecture. Nord J Psychiatry. 2013;67(1):38–42.
32. Westwood H, Eisler I, Mandy W, Leppanen J, Treasure J, Tchanturia K. Using the autism-Spectrum quotient to measure autistic traits in anorexia nervosa: a systematic review and meta-analysis. J Autism Dev Disord. 2016;46(3):964–77.
33. Lindner SE, Fichter MM, Quadflieg N. Set-shifting and its relation to clinical and personality variables in full recovery of anorexia nervosa. Eur Eat Disord Rev. 2014;22(4):252–9.
34. Oldershaw A, Hambrook D, Tchanturia K, Treasure J, Schmidt U. Emotional theory of mind and emotional awareness in recovered anorexia nervosa patients. Psychosom Med. 2011;73(1):73–9.
35. Dapelo MM, Hart S, Hale C, Morris R, Tchanturia K. Expression of positive emotions differs in illness and recovery in anorexia nervosa. Psychiatry Res. 2016;246:48–51.
36. Anckarsater H, Hofvander B, Billstedt E, Gillberg IC, Gillberg C, Wentz E, Rastam M. The sociocommunicative deficit subgroup in anorexia nervosa: autism spectrum disorders and neurocognition in a community-based, longitudinal study. Psychol Med. 2012;42(9):1957–67.
37. Tchanturia K, Larsson E, Adamson J. How anorexia nervosa patients with high and low autistic traits respond to group cognitive remediation therapy. Bmc Psychiatry. 2016;16:334.
38. Duclova J, Kocourkova J, Koutek J. Early-onset anorexia nervosa in girls with Asperger syndrome. Neuropsychiatr Dis Treat. 2015;11:1639–43.
39. Spain D, Sin J, Chalder T, Murphy D, Happe F. Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: a review. Res Autism Spectr Disord. 2015;9:151–62.
40. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
41. Oldershaw A, Delong H, Hambrook D, Broadbent H, Tchanturia K, Treasure J, Schmidt U. Emotional processing following recovery from anorexia nervosa. Eur Eat Disord Rev. 2012;20(6):502–9.
42. Westwood H, Mandy W, Tchanturia K. Clinical evaluation of autistic symptoms in a adult females with anorexia nervosa. Mol Autism. 2017;16(8):12.
43. Westwood H, Mandy W, Tchanturia K. Assessing ASD in adolescent females with anorexia nervosa using clinical and developmental measures: a preliminary investigation. J Abnorm Child Psychol. 2017; doi:10.1007/s10802-017-0301-x.
44. Horne DJD. Individual case formulation. Clin Psychol. 2013;17(3):134–5.
45. Luborsky L, Mcclellan AT, Woody GE, Obrien CP, Auerbach A. Therapist success and its determinants. Arch Gen Psychiatry. 1985;42(6):602–11.
46. Grainger C, Williams DM, Lind SE. Metacognitive monitoring and control processes in children with autism spectrum disorder: diminished judgement of confidence accuracy. Conscious Cogn. 2016;42:65–74.

47. Losh M, Capps L. Understanding of emotional experience in autism: insights from the personal accounts of high-functioning children with autism. Dev Psychol. 2006;42(5):809–18.
48. Moree BN, Davis TE. Cognitive-behavioral therapy for anxiety in children diagnosed with autism spectrum disorders: modification trends. Res Autism Spectr Disord. 2010;4(3):346–54.

Chapter 6: Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment?

Kinnaird, E., Norton, C., Stewart, C. & Tchanturia, K. (2019). Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment? *International Review of Psychiatry, 31*(4), 308-317. doi:10.1080/09540261.2018.1531831

INTERNATIONAL REVIEW OF PSYCHIATRY
2019, VOL. 31, NO. 4, 308–317
https://doi.org/10.1080/09540261.2018.1531831

ORIGINAL RESEARCH

Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment?

Emma Kinnaird[a], Caroline Norton[b], Catherine Stewart[a,b] and Kate Tchanturia[a,b,c]

[a]Institute of Psychiatry, Psychology and Neuroscience, Department of Psychological Medicine, King's College London, London, UK; [b]Eating Disorders National Service, South London and Maudsley NHS Foundation Trust, London, UK; [c]Department of Arts and Sciences, Ilia State University, Tbilisi, Georgia

ABSTRACT

Research suggests that up to one in four individuals with anorexia nervosa (AN) may be on the autistic spectrum, and that these autistic traits may not have been recognized or diagnosed prior to eating disorder (ED) treatment. Significantly, these heightened autistic traits are associated with poorer treatment outcomes, suggesting that treatment may need to be adapted for this population. The purpose of this study was to explore with people with AN on the autistic spectrum their experiences of ED treatment, and their views on what needs to be changed. Women with AN (n= 13), either with an autism diagnosis or presenting with clinically significant levels of autistic traits, were interviewed on their experiences of treatment and potential improvements. Interviews were analysed using thematic analysis. The findings suggest that this population experience unique needs associated with their autism that are not being met by standard ED treatments, and recommendations are made for potential future adaptations. Future research into a more systematic approach for treatment adaptations for this population, including education programmes for clinicians, could potentially lead to better treatment experiences.

ARTICLE HISTORY
Received 23 July 2018
Accepted 30 September 2018

KEYWORDS
Qualitative; autism; anorexia; treatment; comorbidity

Introduction

Anorexia nervosa (AN) is a severe and enduring eating disorder (ED) characterized by the restriction of energy intake leading to low body weight, an intense fear of weight gain, and the undue influence of shape and weight on self-evaluation (APA, 2013). Autism is a neurodevelopmental condition with onset in the early developmental period, presenting with difficulties in social and communicative functioning and restricted behavioural patterns (APA, 2013).

It is well established that autistic people experience elevated rates of mental health problems compared to their neurotypical counterparts: 70% of autistic children exhibit at least one co-occurring psychiatric illness, with anxiety and depression amongst the most common disorders (Simonoff et al., 2008; Strang et al., 2012). However, recent literature indicates that there may be a previously under-explored association between autism and EDs (Karjalainen, Gillberg, Rastam, & Wentz, 2016). Research suggests that a significant minority of people with AN in fact have underlying, potentially undiagnosed, autism (Tchanturia et al., 2013; Westwood, Mandy, & Tchanturia, 2017). A systematic review found that, potentially, one in four women with AN are autistic, compared to a prevalence rate of ~1% in the general population (Scott, Baron-Cohen, Bolton, & Brayne, 2002). However, understanding the exact prevalence of autism in AN is complicated: emerging evidence suggests that there may be a 'female phenotype' of autism characterized by fewer repetitive behaviours, different types of restricted interests, and the capacity to 'camouflage' their social difficulties (Mandy et al., 2012; Rynkiewicz et al., 2016). Consequently, there is a risk that current standard diagnostic tools developed from research using predominantly male samples may lack sensitivity in diagnosing women (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015).

Potential mechanisms underlying the relationship between AN and autism could include shared cognitive traits: commonly with research in autism, literature shows that people with AN exhibit problems with rigidity, central coherence, and emotional and social

CONTACT Kate Tchanturia kate.tchanturia@kcl.ac.uk Section of Eating Disorders, Institute of Psychiatry, Psychology and Neuroscience, Department of Psychological Medicine, King's College London, 103 Denmark Hill, London SE5 8AZ, UK

Supplemental data for this article can be accessed at https://doi.org/10.1080/09540261.2018.1531831.

processing that may persist following recovery (Harrison, Mountford, & Tchanturia, 2014; Lang et al., 2016a, 2016b; Lang, Lopez, Stahl, Tchanturia, & Treasure, 2014; Leppanen, Sedgewick, Treasure, & Tchanturia, 2018; Westwood, Lawrence, Fleming, & Tchanturia, 2016; Westwood, Stahl, Mandy, & Tchanturia, 2016). Significantly, heightened autistic traits in people with AN are associated with more severe presentations and poorer treatment outcomes (Nielsen, Anckarsater, Gillberg, Rastam, & Wentz, 2015; Tchanturia, Adamson, Leppanen, & Westwood, 2017; Tchanturia, Larsson, & Adamson, 2016), leading to suggestions that traditional treatment approaches may need to be adapted for this population (Dudova, Kocourkova, & Koutek, 2015; Stewart, McEwen, Konstantellou, Eisler, & Simic, 2017; Treasure, 2013). Although at present there is a lack of research in this area, potential contributors behind these poorer outcomes could reflect the heightened rigidity and difficulties with introspection seen in autism, making it difficult for patients to engage in treatment (Dudova et al., 2015). Similarly, autistic people with co-occurring AN could experience factors motivating their ED behaviours that are related to their autism, rather than the traditional shape and weight concerns associated with AN: studies of food selectivity in autistic individuals suggest that factors impacting eating in this population could include sensory sensitivity, a need for routine and difficulties with coordination (Cermak, Curtin, & Bandini, 2010). A study interviewing clinicians on their views on treating AN in autistic patients found that clinicians felt that this population was particularly difficult to treat (Kinnaird, Norton, & Tchanturia, 2017). Problems inhibiting treatment included rigid thought patterns, difficulties with emotion identification, and communication. Clinicians identified the importance of understanding the role of autism in the ED, and the identification of autistic traits and referral for diagnosis if necessary. However, many clinicians felt that they did not have enough information or training in this area.

Consequently, previous research indicates that people with AN on the autistic spectrum could benefit from treatment adaptations (Kinnaird et al., 2017). Nonetheless, at present there is a lack of literature on the needs of this population, and how treatment should, therefore, be adapted. At present, any changes to treatment are typically made on the basis of individual clinician experience, rather than representing a systematic approach (Kinnaird et al., 2017). Research has explored how treatment for other psychological conditions should be adapted for autistic people, including adapting cognitive behavioural therapy for anxiety and depression, but no research has explored treatment adaptations for AN (Moree & Davis, 2010; Spain, Sin, Chalder, Murphy, & Happe, 2015). Therefore, the aim of this study was to examine the possibility of treatment adaptations for this population by exploring the views and experiences of individuals with AN on the autistic spectrum.

Method

Study design

Semi-structured interviews were conducted with women with AN and high levels of autistic traits between August 2017 and May 2018. The study received ethical approval from London-City and East Research Ethics Committee and South London (18/LO/0050) and Maudsley Clinical Audit & Effectiveness Committee.

Participant selection

Patients with AN receiving treatment with the National Eating Disorder Clinical Service in South London and Maudsley NHS Foundation Trust were invited to participate in the study by their clinicians if they had a diagnosis of autism or had scores indicative of high autistic traits on the Short Autism Spectrum Quotient (AQ-10) or the Autism Diagnostic Observation Schedule (ADOS) (Allison, Auyeung, & Baron-Cohen, 2012; Lord et al., 2000). The AQ-10 is a brief screening instrument designed to measure autistic traits and guide decision-making around referral for a formal diagnosis. Participants were invited to the study if they scored above the previously established clinical cut-off (6). The ADOS is a structured interview designed for the direct observation of characteristics associated with autism. Participants were considered eligible if they scored above the threshold for being on the autism spectrum. Eligible patients were informed that they were being invited to participate in an interview on their treatment experiences. If patients expressed interest and gave verbal consent, a meeting at their place of treatment with the study's researcher (EK) was arranged to discuss the study and, if the patient was still interested, conduct the interview.

In addition, participants were invited through a separate online study on autism and eating behaviours if they self-reported having both a diagnosis of autism and AN, and having previously experienced AN treatment. Potential participants were contacted by the first author and invited to participate in an interview

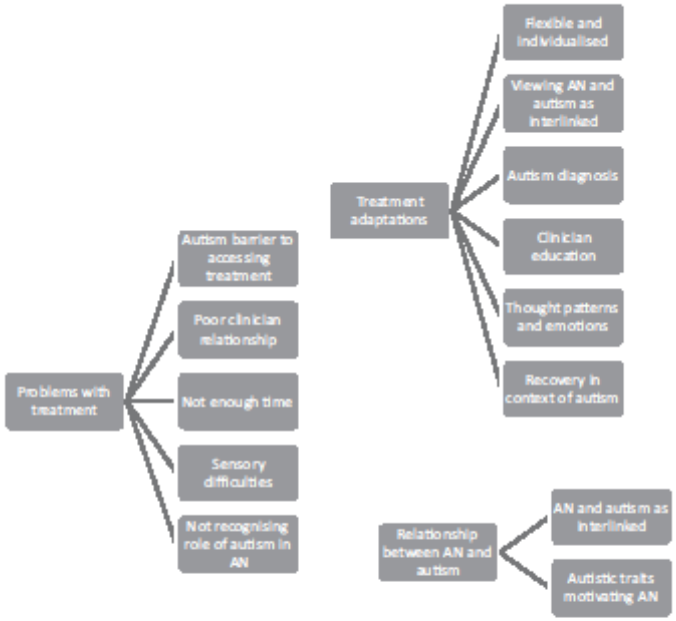


Figure 1. Thematic map of themes and sub-themes.

on their ED treatment experiences. Interested participants were then interviewed face to face, over the phone, Skype, or instant messenger, depending on participant preference. This recruitment process continued until authors EK and KT judged that data saturation had been reached.

Participant characteristics

In total, 16 people were invited to participate in the study; three declined, two without giving a reason and one person due to their social anxiety making interviewing prohibitive. The final study sample consisted of 13 participants who had previously received treatment for AN, with a mean age of 28.46 years (SD = 7.21). Five participants were recruited through the inpatient service, with the remaining eight recruited online. Eleven participants identified as female, whilst two identified as non-binary. Nine participants had been diagnosed with autism. Four participants exhibited high levels of autistic traits, but no confirmed diagnosis: three of these participants scored above cut-off on the TQ-10, and one participant met the threshold for autism on the ADOS. Out of the nine participants with diagnosed autism, the average age of diagnosis was 23.56 years (SD = 8.17). Individuals in the study had received treatment in varying geographical locations across the UK, the US, and Western European countries.

Participants had been ill with AN for an average of 8.42 years (SD = 7.03), with the majority ($n = 10$, 77%) of participants receiving treatment on multiple occasions over the course of their illness. Twelve out of the 13 participants (93%) had also been diagnosed with other psychiatric illnesses: eight with depression, eight with anxiety, six with obsessive compulsive disorder, two with bipolar disorder, two with post-traumatic stress disorder, and one with Tourette's. Additionally, two participants had been diagnosed over the course of their treatment with borderline personality disorder, but disputed this diagnosis.

Data collection

Interviews were conducted by EK at a time and using a method of the participant's choosing. Six interviews were conducted face-to-face at the participant's place of treatment, one over the telephone, three using Skype, and three using an instant messaging service. Prior to each interview, participants were provided with written information on the study and given an opportunity to ask questions before securing written

informed consent. Each interview lasted between 15–45 min and was audio-recorded. The interviews were conducted using a semi-structured topic guide, exploring participant experiences of treatment and what could be improved. If the participant had a diagnosis of autism they were additionally asked to reflect upon how their autism may have affected their treatment, and how treatment could be improved specifically for autistic people with AN in the future. The interview guide was based on topics thought to be relevant to this area based on previous research, and additionally was developed with the help of an autistic individual who had previously received treatment for AN. As interviews progressed and as new, previously unconsidered topics were raised by the participants, these new topics were added to the interview guide. This process continued until no new topics were raised, indicating data saturation.

Analysis

The interviews were transcribed by EK and entered into NVivo (version 11) for analysis. All identifying information was removed at the point of transcription. Interview data was analysed using thematic analysis: first, interview transcripts were read and reread by authors EK and KT to ensure familiarization (Braun & Clarke, 2006). A coding framework was then developed based on the final interview schedule, which had been updated during the interview process to capture all topics raised by participants. A copy of the final interview schedule is available in the Supplementary material for this paper. These codes were then applied line by line to the data. Following coding, data within each code was reread and compared to identify patterns. Three themes were identified as reflecting these patterns: the relationship between autism and anorexia, problems with treatment, and treatment adaptations.

Results

Themes and sub-themes are summarized in a thematic map in Figure 1. Key findings are summarized below under their main theme headings.

Relationship between autism and anorexia

For participants with an autism diagnosis, all saw their AN and their autism as deeply interlinked. First, they felt that traits associated with their autism in turn reinforced their AN, both contributing towards its development and making recovery more challenging. A common difficulty described by participants was that the rigidity and inflexibility associated with their autism had contributed towards the development of fixed routines and rituals around food, and that, once these had developed, this same rigidity made it very difficult for them to change.

Second, participants described how certain traits and behaviours associated with their autism contributed to the development of their AN, but in ways not traditionally associated with ED behaviours and so not addressed or recognised by current treatment models. Participants described how a desire to lose weight, low self-esteem, and body image issues were less relevant in the development of their illness compared to other, non-traditional motivations. Although these varied across participants, motivations included a need for control, rigid thought patterns, sensory difficulties, social confusion or struggling to relate to other people, organizational problems surrounding cooking and food shopping, exercise as a method of stimulation, and the ED acting as a special interest. For many participants, AN became a way of coping with these difficulties:

> I've never really had the thoughts of I want to, kind of, I don't know, be really thin or lose weight. I've never really—like it's always just kind of happened. And I think it's not like—it is a bit about body image that everything like that but … It's more kind of a way of dealing with sensory things like, yeah, it's a massive thing of not knowing that I had sensory issues and it as a way of coping with those (Participant 9).

The majority of participants diagnosed with autism in this study only received their diagnosis upon receiving ED treatment. As highlighted by this participant, the development of AN was not only viewed as a way of coping with autistic traits, but as a way of coping with autistic traits that these participants were not aware they had as they had not yet been diagnosed. Rather, AN became a way of managing these difficulties and, often, a feeling of difference that they did not understand.

Problems with treatment

For the minority of participants who had received an autism diagnosis prior to ED treatment, a common experience was that they found it difficult to access treatment due to their co-occurring autism. Participants described being refused treatment by specialist ED services. Where participants did access ED treatments, they were often seen as difficult or

uncooperative patients due to their (typically undiagnosed) autism, which led to a poor relationship with clinicians and participants leaving or being discharged from services:

> The first facility I went to, before the autism diagnosis was problematic because they thought that I was stubborn and lazy and unwilling to help myself, and they let me know it. They ended up asking me not to come back, because my case was too "complex" (Participant 5).

Similarly, participants described struggling to make progress within the typical time frames for treatment, and being discharged for not making enough progress with treatment. In addition to the lack of time, participants highlighted a number of problems with the treatments they were offered for their ED. In particular, they felt that their autistic traits and behaviours made it difficult for them to engage with treatment in ways that were not recognized or misinterpreted by clinicians. Participants described how their sensory and social difficulties made inpatient treatment environments extremely challenging and often upsetting:

> I'm very very sensitive to noise. You know, extremely sensitive. Like things like laughter and stuff, I can pick it up so easily and I don't like loud noises, like when someone's distressed in the room I get very distressed, it makes me feel distressed … I feel like they didn't understand that I needed to walk out, because apparently, they handed it over to the other staff for my notes. I feel like they don't understand I took myself out of the situation because I can't cope with the noise (Participant 1).

Similarly, participants whose eating behaviours were partially motivated by sensory difficulties around food described struggling with refeeding programmes that did not take these problems into account. Difficulties included sensitivity to taste, smells, texture, aversion to mixing foods, and needing to have foods at certain temperatures. Participants described their frustration when they were willing to eat food whilst adapting around their autism, such as avoiding certain textures or maintaining a routine, and having this misinterpreted by staff as ED behaviours:

> It was sensory and texture and just, caused me so much anxiety not because of what food it was but because of like the sensory aspect of that food … it was always kind of acted as though I was just not really aware and it was really the food that was causing me distress. And then that made me more angry because it felt like they were saying I was lying (Participant 10).

Participants described the lack of recognition of the relationship between their autism and their eating behaviours, and an unwillingness to accommodate these difficulties, as a key factor in impeding their nutritional recovery.

Consequently, participants struggled when treatment was aimed at changing apparent ED behaviours that were in fact related to their autism, and felt misunderstood by their clinicians. In some cases, this misinterpretation of autism related behaviours led to what participants felt were misdiagnoses, including autistic meltdowns being misinterpreted as anxiety or borderline personality disorder, leading to inappropriate treatment interventions and continuing deteriorating relationships with clinicians.

Treatment adaptations

In the context of these difficulties with treatment, and the relationship between autism and AN, participants reflected on potential treatment adaptations. Participants felt that traditional ED approaches needed to be adapted for people on the autistic spectrum, and described wanting a flexible, individualized approach which recognized the role of their autism in their ED:

> Treating the AN as though it exists in a vacuum is incredibly harmful, because it's demoralizing to the patient, it delays recovery, and it frustrates everyone involved. Emphasis needs to be placed on figuring out which behaviours are anorexia based, and which are autism based. If someone is refusing to eat their dinner, it could be because their eating disorder is telling them that it will make them fat, or, the food could be touching, is an autistic sensory issue. The behaviours are exactly the same, but the causes can be so different. Knowing all of this, if doctors and therapists and dieticians can be flexible regarding autistic patients, they're going to see much better outcomes (Participant 5).

For many participants a key element in their treatment was having their autism recognized and finally diagnosed. The majority of participants with an autism diagnosis in this study received this diagnosis as a result of accessing ED treatment, where their autism was recognized for the first time. Where clinicians did recognize the presence of autistic traits and refer for a diagnosis, this was viewed as a positive, important experience for participants:

> Actually, all this mental health stuff that I've had—this is why, this is why I've felt like I've not fitted into the world for the last 45 years, and actually I'm just different and that's ok (Participant 10).

Having an autism diagnosis also enabled participants to have better insight into their ED behaviours,

allowing them to explore and understand which behaviours were related to their ED, and which were in fact related to their autism. This gave them more confidence in treatment to voice and describe their own needs to their clinicians, leading to a better overall treatment experience:

> I have like sensory issues with touch, for example textures. But that's something, like last time because I think I was masking I wouldn't bring it up. And it takes quite a lot of courage to be honest and say "actually, yeah, that's a sensory thing for me", or, I don't know if this is sensory but ever since I've been a child I've never really liked my food mixed or touching. But again, like last time I kind of thought "oh well to recover you have to mix your foods" so, I don't know, it was almost like masking the recovery (Participant 9).

Other treatment improvements described by participants included the importance of clinicians having an understanding of autism and its implications for the ED and its treatment, and a willingness to adapt around difficulties relating to the autism. When participants felt that they were being listened to, and able to direct and influence their treatment to adapt to their autism in collaboration with the clinician, they described better treatment experiences and outcomes. Some participants described specific changes or improvements to ED treatment. In particular, participants felt that current treatment approaches did not take into account their autistic traits and behaviours motivating the ED:

> I know that their model of therapy is not going to deal with that. I, so, it's not going to address what I think—I think my problem is how I think. I think, I think as somebody who's on the autistic spectrum and who has an ED, I think AN is kind of like a product of who I am and how I think (Participant 6).

Consequently, this participant felt that treatment could be improved by targeting the rigid thought patterns associated with autism. Whilst participants emphasized that the influence of autism on the ED would vary across individuals, other possible improvements included work on identifying and describing emotions, allowing participants who struggled with communication to write things down in between therapy appointments, a sensory space to withdraw to, and occupational therapy support with difficulties surrounding cooking, food shopping, and organization. In addition, participants felt that they potentially needed more time in treatment, due to the difficulty of challenging the rigidity and routine behaviours associated with autism.

Significantly for treatment, participants felt that their underlying autism impacted how they viewed recovery. Some participants felt unsure if they would ever fully recover, as their ED had become a key part of their life. Participants who had recovered described still having certain behaviours around food, such as a need for control, which they viewed as stemming from their autism rather than their AN. Consequently, one participant felt that recovery for autistic people was less associated with eliminating all food related behaviours, and should be focused on working towards a good quality of life:

> Obviously people need to be having a good diet, and they need to be getting to a sustainable weight, and like not having everything controlled, but people getting that like someone is going to still have, probably, a rigidity around their food, like and that not being totally—not just in inpatient, in outpatient as well—that's not the battle to be fighting. It should be about how much is that person able to now be like engaging in life (Participant 13).

Discussion

The findings of this study suggest that people with AN on the autism spectrum have unique needs relating to their autistic traits that require treatment adaptations. The participants in this study highlighted the importance of exploring and understanding collaboratively with clinicians the relationship between their ED and their autistic traits, and the need to recognize these traits and make appropriate adaptations in treatment.

Whilst previous research has highlighted the prevalence of autism in people with AN, this present study went further in exploring the role that autistic traits potentially play in the development and maintenance of the ED (Westwood & Tchanturia, 2017). That participants felt that their autistic traits, including difficulties with rigidity, inflexibility, and social processing, contributed to and maintained their illness reflects research suggesting that these cognitive characteristics may act as maintenance factors for AN, leading to poorer treatment outcomes (Schulte-Ruther, Mainz, Fink, Herpertz-Dahlmann, & Konrad, 2012; Treasure, 2013; Treasure & Schmidt, 2013). Moreover, participants highlighted a number of other difficulties associated with their autism that motivated their ED behaviours not addressed by traditional models of AN, including sensory sensitivity, and executive functioning problems creating difficulties around cooking (Cermak et al., 2010; Crane, Goddard, & Pring, 2009; Hill, 2004). That sensory

difficulties were highlighted by the participants in this study is striking in the context of recent literature suggesting that sensory sensitivity to food may be altered in AN, and the possibility that sensory sensitivity could represent a shared mechanism in autism and AN warrants future research (Kinnaird, Stewart, & Tchanturia, 2018).

The findings of this current study examining patient views on treating anorexia in autistic people generally resonate with a previous study exploring clinician views on this same topic, with the experiences of patients giving greater insight into the difficulties raised by clinicians (Kinnaird et al., 2017). One common aspect was that of understanding recovery in the context of autism: both patients and clinicians emphasized that certain behaviours relating to the autism, such as difficulty with rigidity or food sensory issues, may persist following recovery. Consequently, clinicians treating autistic patients should consider how their patient views recovery, which behaviours are ED related and so can be targeted for change, and which behaviours are rooted in the autism and so may require a process of adaptation and acceptance.

A key divergence in the views of the two groups was that of communication difficulties. Clinicians raised the problem of communication problems, describing autistic patients as difficult to functionally communicate with, and highlighting issues such as patients giving only brief responses, being difficult to engage in conversation, or needing clear and unambiguous instructions using literal language. This is in contrast to the interviews conducted in this study: far from being brief, participants often gave lengthy and detailed responses to the interview questions and were highly engaged. This may in part reflect that, rather than using only face-to-face interactions as typical in therapy sessions, the present study allowed participants to choose how they were interviewed, including over instant messenger. That patient interaction may improve through using alternative methods of communication, including writing things down, reflects previous clinician recommendations for autistic patients (Kinnaird et al., 2017).

In contrast to the views of clinicians that patients were uncommunicative, patients highlighted that they also experience communication difficulties in this relationship, but from a perspective of a lack of understanding, describing a feeling of not being listened to or believed, and clinicians not allowing them to have an input into their treatment. That individuals on both sides of the clinician/patient dyad highlight communication problems with their opposite number reflects a growing interest in the 'double empathy' problem in autism: that communication difficulties do not stem from the autistic person alone, but rather due to two people with very different experiences interacting (Milton, 2012). In the case of this population, this could reflect a barrier between a clinician with a neurotypical perspective of how an ED typically presents and lacking insight into the autistic experience, and an autistic patient whose ED experiences are in fact deeply informed by their autism. The findings of both this current study and the previous clinician study suggest that an individualized approach, where a clinician informed and trained in working with autistic people prioritizes the patient's input on their treatment and encourages and values their input, may be vital in addressing these mutual communication difficulties.

Nonetheless, at present clinicians working in ED settings do not typically receive systematic training in autism, and report lacking the knowledge or confidence to make the kinds of adaptations required for this population (Kinnaird et al., 2017). This reflects wider difficulties that autistic people experience in accessing health services, with previous research similarly finding high levels of unmet needs, and the perception of autistic service users that these needs are misunderstood or dismissed (Nicolaidis et al., 2013; Tint & Weiss, 2017). This study also reinforces the finding of past research suggesting that treatment spaces are often not autism friendly, including difficulties with sensory sensitivity and over-stimulation, suggesting that ED treatment spaces—particularly inpatient wards—may need to be adapted for this population (Tint & Weiss, 2017). In the present study, this poor service experience was often related by participants to clinicians not recognizing or understanding the role of their autism in their ED, emphasizing the importance of clinician education in this area (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012).

Unlike previous research on the service needs of autistic adults, a key problem raised in this study unique to this population was that many participants described not realizing they had autism until they accessed ED treatment. This reflects research findings that women are diagnosed with autism at a later age compared to men, and that their autistic traits may go unrecognized (Begeer et al., 2013; Rutherford et al., 2016). In this study, participants directly related their autism being undiagnosed and the development of AN as a coping mechanism for their autistic traits. Consequently, this highlights the importance of autism being recognized and diagnosed in people with

AN to enable effective treatment. Given the heightened prevalence of autism in people with AN, this potentially suggests a need for a systematic screening approach for heightened ASD traits in people seeking treatment (Westwood et al., 2017).

This was a qualitative study, and so only represents the experiences of a minority of people on the autistic spectrum who have received treatment for AN. However, this study did recruit participants from varying geographical locations and health service systems, supporting the generalizability of these findings. Future empirical research should further explore the relationship between autism and AN identified in this study, and how the ED pathology of people on the autistic spectrum differs from those with AN only. In particular, the concept raised by participants in this study that autism contributed to the development of their AN should be explored by longitudinal research. Further research should explore the possibility of developing a more systematic approach to treatment adaptations for people with AN on the autistic spectrum, including clinician training and the possibility of structured interventions for traits such as cognitive rigidity, communication difficulties, or emotional processing. These adaptations could then be evaluated in a controlled study design against standard treatment.

Clinical implications

The findings of these paper raise a number of potential treatment adaptations for this population which should be explored in future empirical research. The role of autistic traits in the ED needs to be recognized and addressed in treatment, and emphasizes the importance of clinician education and training in autism and its potential role in the ED. Specific interventions could include cognitive remediation to address rigid and inflexible thought patterns, or work on recognizing and expressing emotions using emotion skills training (Easter & Tchanturia, 2011; Kyriacou, Easter, & Tchanturia, 2009; Money, Genders, Treasure, Schmidt, & Tchanturia, 2011; Tchanturia, Doris, Mountford, & Fleming, 2015). Furthermore, sensory sensitivity to food in autism may indicate a need to adapt refeeding programmes in order to accommodate these sensitivities, and so create a sustainable nutritional recovery (Cermak et al., 2010). Clinician training could also be valuable in addressing the communication difficulties raised in the present study and previous research (Kinnaird et al., 2017). Any adaptations should reflect an individualized, collaborative approach between patient and clinician, with a focus on autism recognition and diagnosis.

Conclusions

People with AN on the autism spectrum experience their autism and their ED as deeply interlinked, with their autistic traits motivating apparent ED behaviours in ways that are not accounted for by traditional treatment models. At present, these unique needs are not being met by standard treatment approaches. Consequently, treatment adaptations are required for this population.

Acknowledgements

The authors would like to thank the participants in this study for contributing their time and their experiences to this research.

Disclosure statement

This paper represents independent research. KT would like to acknowledge financial support from MRC and MRF Child and young adult Mental health—the underpinning aetiology of self-harm and eating disorders. EK received PhD funding for this project through the Medical Research Council Doctoral Training Partnership (MRC DTP) scheme (MR/N013700/1).

Informed Consent

Written informed consent was obtained from all participants prior to data collection.

ORCID

Emma Kinnaird http://orcid.org/0000-0002-6821-8386
Kate Tchanturia http://orcid.org/0000-0001-8988-3265

References

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief "Red Flags" for autism screening: The short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(2), 202–212. doi:10.1016/j.jaac.2011.11.003

American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of*

Autism and Developmental Disorders, *43*(5), 1151–1156. doi:10.1007/s10803-012-1656-z

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. doi:10.1191/1478088706qp063oa

Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J., & Stein, N. (2012). Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. *Journal of Autism and Developmental Disorders*, *42*(11), 2498–2504. doi:10.1007/s10803-012-1496-x

Cermak, S. A., Curtin, C., & Bandini, L. G. (2010). Food selectivity and sensory sensitivity in children with autism spectrum disorders. *Journal of the American Dietetic Association*, *110*(2), 238–246. doi:10.1016/j.jada.2009.10.032

Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. *Autism*, *13*(3), 215–228. doi:10.1177/1362361309103794

Dudova, I., Kocourkova, J., & Koutek, J. (2015). Early-onset anorexia nervosa in girls with Asperger syndrome. *Neuropsychiatric Disease and Treatment*, *11*, 1639–1643. doi:10.2147/ndt.s83831

Easter, A., & Tchanturia, K. (2011). Therapists' experiences of Cognitive Remediation Therapy for anorexia nervosa: Implications for working with adolescents. *Clinical Child Psychology and Psychiatry*, *16*(2), 233–246. doi:10.1177/1359104511401185

Harrison, A., Mountford, V. A., & Tchanturia, K. (2014). Social anhedonia and work and social functioning in the acute and recovered phases of eating disorders. *Psychiatry Research*, *218*(1-2), 187–194. doi:10.1016/j.psychres.2014.04.007

Hill, E. L. (2004). Evaluating the theory of executive dysfunction in autism. *Developmental Review*, *24*(2), 189–233. doi:https://doi.org/10.1016/j.dr.2004.01.001

Karjalainen, L., Gillberg, C., Rastam, M., & Wentz, E. (2016). Eating disorders and eating pathology in young adult and adult patients with ESSENCE. *Comprehensive Psychiatry*, *66*, 79–86. doi:10.1016/j.comppsych.2015.12.009

Kinnaird, E., Norton, C., & Tchanturia, K. (2017). Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: A qualitative study. *BMC Psychiatry*, *17*, 292. doi:10.1186/s12888-017-1455-3

Kinnaird, E., Stewart, C., & Tchanturia, K. (2018). Taste sensitvity in anorexia nervosa: A systematic review. *International Journal of Eating Disorders*, *00*, 1–14. doi:10.1002/eat.22886

Kyriacou, O., Easter, A., & Tchanturia, K. (2009). Comparing views of patients, parents and clinicians on emotions in anorexia: A qualitative study. *Journal of Health Psychology*, *14*(7), 843–854. doi:10.1177/1359105309340977

Lai, M. C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: Setting the science for future research. *Journal of the American Academy of Child and Adolescent Psychiatry*, *54*(1), 11–24. doi:10.1016/j.jaac.2014.10.003

Lang, K., Larsson, E. E. C., Mavromara, L., Simic, M., Treasure, J., & Tchanturia, K. (2016). Diminished facial emotion expression and associated clinical characteristics in Anorexia Nervosa. *Psychiatry Research*, *236*, 165–172. doi:10.1016/j.psychres.2015.12.004

Lang, K., Lopez, C., Stahl, D., Tchanturia, K., & Treasure, J. (2014). Central coherence in eating disorders: An updated systematic review and meta-analysis. *World Journal of Biological Psychiatry*, *15*(8), 586–598. doi:10.3109/15622975.2014.909606

Lang, K., Roberts, M., Harrison, A., Lopez, C., Goddard, E., Khondoker, M., … Tchanturia, K. (2016). Central coherence in eating disorders: A synthesis of studies using the Rey Osterrieth Complex Figure Test. *Plos One*, *11*(11), e0165467. doi:10.1371/journal.pone.0165467

Leppanen, J., Sedgewick, F., Treasure, J., & Tchanturia, K. (2018). Differences in the Theory of Mind profiles of patients with anorexia nervosa and individuals on the autism spectrum: A meta-analytic review. *Neuroscience & Biobehavioral Reviews*, *90*, 146–163. doi:10.1016/j.neubiorev.2018.04.009

Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. C., … Rutter, M. (2000). The autism diagnostic observation schedule—generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, *30*(3), 205–223. doi:10.1023/a:1005592401947

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, *42*(7), 1304–1313. doi:10.1007/s10803-011-1356-0

Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, *27*(6), 883–887. doi:10.1080/09687599.2012.710008

Money, C., Genders, R., Treasure, J., Schmidt, U., & Tchanturia, K. (2011). A brief emotion focused intervention for inpatients with anorexia nervosa: A qualitative study. *Journal of Health Psychology*, *16*(6), 947–958. doi:10.1177/1359105310396395

Moree, B. N., & Davis, T. E. (2010). Cognitive-behavioral therapy for anxiety in children diagnosed with autism spectrum disorders: Modification trends. *Research in Autism Spectrum Disorders*, *4*(3), 346–354. doi:10.1016/j.rasd.2009.10.015

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*, *28*(6), 761–769. doi:10.1007/s11606-012-2262-7

Nielsen, S., Anckarsater, H., Gillberg, C., Rastam, M., & Wentz, E. (2015). Effects of autism spectrum disorders on outcome in teenage-onset anorexia nervosa evaluated by the Morgan-Russell outcome assessment schedule: A controlled community-based study. *Molecular Autism*, *6*. doi:10.1186/s13229-015-0013-4

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., … Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with

autism spectrum disorder. *Autism*, *20*(5), 628–634. doi:10.1177/1362361315617879

Rynkiewicz, A., Schuller, B., Marchi, E., Piana, S., Camurri, A., Lassalle, A., & Baron-Cohen, S. (2016). An investigation of the 'female camouflage effect' in autism using a computerized ADOS-2 and a test of sex/gender differences. *Molecular Autism*, *7*(10). doi:10.1186/s13229-016-0073-0

Schulte-Ruther, M., Mainz, V., Fink, G. R., Herpertz-Dahlmann, B., & Konrad, K. (2012). Theory of mind and the brain in anorexia nervosa: Relation to treatment outcome. *Journal of the American Academy of Child and Adolescent Psychiatry*, *51*(8), 832–841. doi:10.1016/j.jaac.2012.06.007

Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). Brief report - Prevalence of autism spectrum conditions in children aged 5-11 years in Cambridgeshire, UK. *Autism*, *6*(3), 231–237. doi:10.1177/1362361302006003002

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, *47*(8), 912–929. doi:10.1097/CHI.0b013e318179964f

Spain, D., Sin, J., Chalder, T., Murphy, D., & Happe, F. (2015). Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review. *Research in Autism Spectrum Disorders*, *9*, 151–162. doi:10.1016/j.rasd.2014.10.019

Stewart, C. S., McEwen, F. S., Konstantellou, A., Eisler, I., & Simic, M. (2017). Impact of ASD traits on treatment outcomes of eating disorders in girls. *European Eating Disorders Review*, *25*(2), 123–128. doi:10.1002/erv.2497

Strang, J. F., Kenworthy, L., Daniolos, P., Case, L., Wills, M. C., Martin, A., & Wallace, G. L. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research in Autism Spectrum Disorders*, *6*(1), 406–412. doi:10.1016/j.rasd.2011.06.015

Tchanturia, K., Adamson, J., Leppanen, J., & Westwood, H. (2017). Characteristics of autism spectrum disorder in anorexia nervosa: A naturalistic study in an inpatient treatment programme. *Autism*. doi:10.1177/1362361317722431

Tchanturia, K., Doris, E., Mountford, V., & Fleming, C. (2015). Cognitive Remediation and Emotion Skills Training (CREST) for anorexia nervosa in individual format: Self-reported outcomes. *BMC Psychiatry*, *15*(53). doi:10.1186/s12888-015-0434-9

Tchanturia, K., Larsson, E., & Adamson, J. (2016). How anorexia nervosa patients with high and low autistic traits respond to group Cognitive Remediation Therapy. *BMC Psychiatry*, *16*(334). doi:10.1186/s12888-016-1044-x

Tchanturia, K., Smith, E., Weineck, F., Fidanboylu, E., Kern, N., Treasure, J., & Cohen, S. B. (2013). Exploring autistic traits in anorexia: a clinical study. *Molecular Autism*, *4*. doi:10.1186/2040-2392-4-44

Tint, A., & Weiss, J. A. (2017). A qualitative study of the service experiences of women with autism spectrum disorder. *Autism*, *22*(8), 928–937. doi:10.1177/1362361317702561

Treasure, J. (2013). Coherence and other autistic spectrum traits and eating disorders: Building from mechanism to treatment. The Birgit Olsson lecture. *Nordic Journal of Psychiatry*, *67*(1), 38–42. doi:10.3109/08039488.2012.674554

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: A summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(13), doi:10.1186/2050-2974-1-13

Westwood, H., Lawrence, V., Fleming, C., & Tchanturia, K. (2016). Exploration of friendship experiences, before and after illness onset in females with anorexia nervosa: A qualitative study. *PLoS One*, *11*(9), e0163528. doi:10.1371/journal.pone.0163528

Westwood, H., Mandy, W., & Tchanturia, K. (2017). Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Molecular Autism*, *8*(12). doi:10.1186/s13229-017-0128-x

Westwood, H., Stahl, D., Mandy, W., & Tchanturia, K. (2016). The set-shifting profiles of anorexia nervosa and autism spectrum disorder using the Wisconsin Card Sorting Test: a systematic review and meta-analysis. *Psychological Medicine*, *46*(9), 1809–1827. doi:10.1017/s0033291716000581

Westwood, H., & Tchanturia, K. (2017). Autism spectrum disorder in anorexia nervosa: An updated literature review. *Current Psychiatry Reports*, *19*(41). doi:10.1007/s11920-017-0791-9

Chapter 7: Carers' views on autism and eating disorders comorbidity: qualitative study

Adamson, J. & Kinnaird, E., Glennon, D., Oakley, M., & Tchanturia, K. (2020). Carers' views on autism and eating disorders comorbidity: qualitative study. *BJPsych Open, 6*(3), e51. doi:10.1192/bjo.2020.36

Due to the low quality of the figure in the published paper as reproduced in this chapter, a higher quality version of the figure is included in Appendix F.

BJPsych Open (2020)
6, e51, 1–6. doi: 10.1192/bjo.2020.36

Carers' views on autism and eating disorders comorbidity: qualitative study

James Adamson*, Emma Kinnaird*, Danielle Glennon, Madeleine Oakley and Kate Tchanturia

Background

Patients with co-occurring anorexia nervosa and autism respond differently to eating disorder treatments. Previous interviews with patients with both conditions and clinicians working in eating disorder services has highlighted service and treatment adaptations might be beneficial and could improve outcomes for these individuals.

Aims

The aim of this study was to explore carers' experiences of current treatment approaches for people with autism who have anorexia nervosa, and their views on how these can be improved.

Method

Ten carers of a loved one diagnosed with autism and anorexia nervosa were interviewed using a semi-structured interview schedule and the transcripts were analysed with thematic analysis.

Results

Four key themes emerged from the interviews: the role of autism in anorexia nervosa, carers' problems with clinical services, the impact on carers and suggestions for future improvements.

Conclusions

Carers agreed that autism played a significant role in the development and maintenance of their daughters' anorexia nervosa. However, this comorbidity does not appear to be appropriately addressed in current treatment provisions. They described several difficulties, including problems getting an autism diagnosis and the perception that eating disorder services did not accept or adapt around the condition. This resulted in feelings of frustration and isolation for families, a scenario exacerbated by a perceived lack of support or specific resources for carers of individuals on the autism spectrum. Clinical recommendations on the basis of the current and previous studies are outlined.

Keywords

Families; carers' needs; autism; eating disorders; treatment adaptation.

Background

The question of whether autism and anorexia nervosa might be linked was highlighted in the research literature as early as 1983,[1] with case studies presented in this area as early as 1988.[2] Autism is a neurodevelopmental condition that is associated with difficulties in social functioning, communication and restricted interests and patterns of behaviour.[3] Anorexia nervosa is a psychiatric disorder characterised by low body weight, fear of gaining weight and severe weight and shape concerns.[3] According to epidemiological studies anorexia nervosa is a disorder that largely affects women, with estimates ranging from 3:1 to 18:1 female to male ratios, and autism is a condition that largely affects men with a 4:1 male to female ratio.[4–7] Women are also more likely to be identified and diagnosed much later in life than men, potentially because of a different clinical presentation that is missed by standard assessment tools.[8,9] There is a growing awareness that previous autism research is male biased, and there have been calls for more research to improve the understanding and recognition of autism in women.[10]

Challenges raised by comorbidity

Although autism and anorexia nervosa represent separate conditions, evidence suggests a number of similarities between these two diagnoses, particularly in the area of cognitive rigidity.[11] In the light of these similarities, various studies conducted in eating disorder settings have examined the prevalence of autism among populations with anorexia nervosa using different tools to measure autistic traits, with estimates ranging from 8 to 37%.[12–14] These findings are replicated in adolescent patients suggesting that adolescents with anorexia nervosa also have elevated autistic features.[15] In patients with anorexia nervosa, higher levels of autistic traits are associated with poorer treatment outcomes, more severe presentations and a longer length of stay in in-patient settings.[16,17] This group of patients also appear to respond to specific elements of treatment differently, for example showing little clinical change after group psychology interventions[18,19] but showing significant improvements after the same intervention delivered in individual formats.[19] Alternatively, autistic traits may be associated with protective factors in treatment: people with autism who have anorexia nervosa may exhibit higher levels of treatment adherence compared with those with anorexia nervosa only.[12] These findings suggest that people with autism may be responding to elements of treatment differently and could benefit from adaptations to the standard anorexia nervosa treatment pathway.

However, there are currently no guidelines for adapting anorexia nervosa treatment for people with autism. In the UK, the National Institute for Health and Care Excellence (NICE) guidelines for Eating Disorders [NG69] has no mention of co-occurring neurodevelopmental disorders, although it does have guidance on physical and mental health comorbidities.[20] Recent qualitative studies interviewing clinicians and patients suggest a clear need for treatment adaptations.[21,22] These studies suggest that although the role of autism in anorexia nervosa needs to be considered during treatment, and appropriate adaptations made accordingly, at present clinicians commonly lack confidence or training in applying these adaptations. However, no research has yet explored the views of carers in this area, despite carers often being expected to be involved in eating disorder treatment.

* Joint first authors.

Aims

Studies suggest that caring for someone with an eating disorder can be difficult for carers, and is often associated with a perceived lack of resources, support and recognition.[2,3,24] To date, no studies have examined how this experience may be affected if the carer is supporting someone with both anorexia nervosa and co-occurring autism. The aim of this study was to explore carers' experiences of current treatment approaches for people with autism who have anorexia nervosa, and their views on how these can be improved. Alongside recent stakeholder interviews with patients and clinicians[21,22] we were particularly interested if there was any overlap with the emerging themes from these previous studies. Integration of these interviews will aid understanding of current treatments for people with autism who have anorexia nervosa and inform future studies on how to adapt treatment to better serve these individuals and their carers.

Method

Semi-structured interviews were conducted with carers who have current or historic caring responsibilities for an individual with both diagnosed autism and anorexia nervosa. Written informed consent was obtained from all participants. The authors assert that all procedures contributing to this work comply with the ethical standards of the Helsinki declaration of 1975, as revised in 2008. Ethical approval was obtained from London-City and East Research Ethics Committee and South London (18/LO/0050).

Recruitment

Participants were recruited through social media, from contact with the study site through previous research and were approached by the principal investigator's (K.T.) contacts. Participants were considered eligible if they had or have had caring responsibility for someone with diagnoses of both autism and anorexia nervosa. The recruitment process continued until all authors agreed data saturation had been reached. After six interviews all authors read the full transcripts and met to agree initial themes, and subsequently met until all authors agreed that saturation had been achieved. Data saturation was judged as the point at which no new information was felt to be emerging from the interviews.

Data collection

Carers were interviewed via skype, phone or in person by author J.A. with interviews lasting between 40 and 60 min. Four carers were interviewed on skype, five via phone call and one in person. Interviews followed a semi-structured format with pre-agreed questions, agreed by the study team and based on questions from previous clinician and patient interviews.[21,22] An example of the types of questions asked were: 'Did you/your loved one experience difficulties accessing clinical services because of co-occurring autism?' and 'Do you feel like the autism was taken into account in previous treatments?'. The full interview schedule is available in supplementary File 1 (available at https://doi.org/10.1192/bjo.2020.36).

Participant characteristics

In total, ten carers completed the interviews. Nine of the participants were mothers to a daughter with both conditions, and one participant was a father. Participants' daughters' ages ranged from 16 to 25 with an average length of an autism diagnosis of 4.9 years and anorexia nervosa diagnosis of 4 years. Three were diagnosed with anorexia nervosa prior to their diagnosis of autism and all had at least one other comorbid diagnosis with the most common being obsessive–compulsive disorder (OCD) and general anxiety disorder. The average age of autism diagnosis for the daughters in this sample was 15 years (9–23 range), this is in the context of a UK national median diagnosis age of 55 months.[25] Nine carers were from different parts of the UK and one carer was from the USA.

Analysis

All interviews were recorded live with Dictaphone software and transcribed. J.A., K.T., M.O. and E.K. individually read each transcript. Authors then met to agree a deductive coding framework based on the research aims and findings from previous research in this area. Authors then individually coded the data line by line. All authors met on two occasions to discuss the coded data and achieve consensus on the themes. Data was analysed using thematic analysis methodology.[26] Four themes emerged from the interviews:

(a) the role of autism in anorexia nervosa;
(b) problems with services;
(c) impact on carers;
(d) and improvements.

Results

The main themes and subthemes are summarised in the thematic map, Fig. 1. Themes and subthemes are summarised under their theme headings.

Role of autism in anorexia nervosa

All carers felt that the anorexia nervosa experienced by their daughters was closely interlinked with their autism, rather than representing separate conditions. They described multiple trait crossovers such as cognitive rigidity, attention to detail and routine behaviours. Carers identified overlaps in behaviours associated with autism and anorexia nervosa, but felt that the mechanisms underlying the behaviours were potentially different for their daughters with autism compared with people with anorexia nervosa only. For example, cognitive rigidity and routine behaviours were identified as existing prior to anorexia nervosa onset, but then worsening with illness development and weight loss.

Autism was also felt to contribute to the development of anorexia nervosa in ways not accounted for in traditional eating disorder formulations. Four carers (40%) believed that anorexia nervosa potentially acted as a coping mechanism for difficulties associated with autism. Similarly, eight carers (80%) identified social difficulties associated with autism as contributing to the development of anorexia nervosa. Many of the carers mentioned that their daughters had the ability to mask their difficulties and appear to be able to cope in some social settings, but this often became difficult as they got older and social situations became more complex, such as starting university. The emergence of anorexia nervosa appeared to be related to this reduced ability to cope:

> 'I realised just how much as a mother and as a family we had been kind of managing her friendships and play dates and I think, as is quite classic as I understand now with female autism especially, that is when really the friends sort of start to drift away, because image is important and the slightly odd friend is not necessarily welcome.' (Carer 7)

All but one of the carers (90%) described sensory issues complicating the anorexia nervosa symptoms and making it hard for clinicians to ascertain what behaviours were because of autism and what were because of anorexia nervosa. This was particularly apparent around food choices, with many carers highlighting that the standard refeeding programme was difficult as the meals often

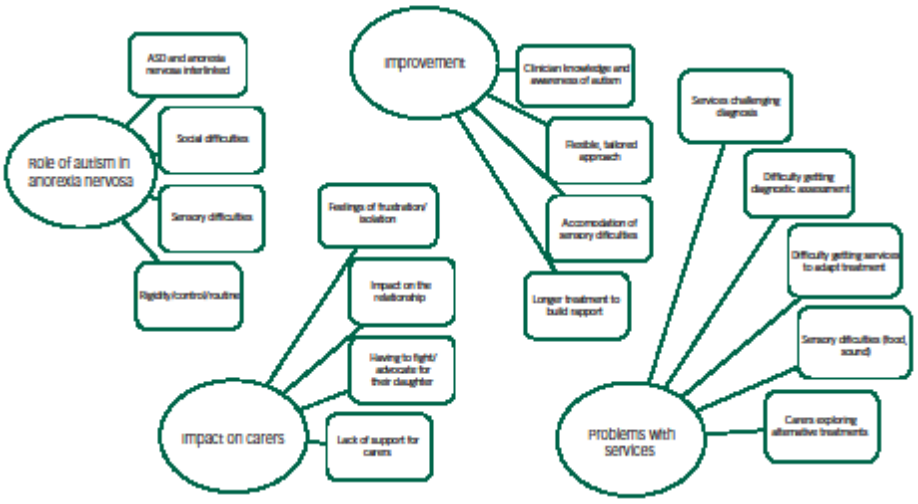


Fig. 1 Main themes and subthemes results from thematic analysis.
ASD, autism spectrum disorder.

involved eating foods that they would not normally eat, or they would have difficulties with the sensory aspect of the food. These difficulties were described as existing from a very early age and therefore pre-dating any anorexia nervosa symptoms. The refeeding programmes would be described as problematic when the food options were too rigid and did not take into account any difficulties with certain foods that existed prior to anorexia nervosa onset.

Problems with services

Carers identified problems with both eating disorder and autism services. Seven carers (70%) described how they had to overcome multiple barriers to get their daughter an autism assessment. Four carers had to pay for a private diagnostic assessment after being turned away from services provided by the National Health Service. Many carers commented on the lack of understanding of female autism in the community and mental health services they approached for assessment, suggesting that either they were not offered an assessment, or received a negative result only to later receive an autism diagnosis.

> 'It was absolutely appalling… particularly poor for girls because, as you probably know, they don't present the same as boys. For years they have been diagnosing girls on the boys' criteria which is hopeless because that is for the boys, not the girls.' (Carer 1, describing their experience of the diagnostic process)

Furthermore, those that did receive an autism diagnosis felt that this then led to problems accessing eating disorder services, including the perception that eating disorder services challenged or refused to acknowledge the autism diagnosis. This often-created tensions between the family and the care team, creating further issues with therapeutic engagement and carer support.

> 'You have to leave the autism at the door, all our girls are like this.' (Carer 2, quoting clinical service response to her informing them of the autism diagnosis)

Even where services did acknowledge the autism diagnosis, carers felt that the clinical teams were unable to make adaptations to the routine anorexia nervosa treatment in order to accommodate any difficulties.

> 'I know she used to zone out in the sessions, and she didn't process what was being said. I asked lots of times for written information. You know, you've got to write it down to explain to her, she has an education, health and care plan; you really need to write it down, she is not processing it and that didn't happen at all, not once.' (Carer 4, talking about her experience of family therapy)

Often treatment environments, especially in-patient settings, were described as not being autism friendly, making it difficult for the individual and their family to engage in traditional treatment settings. For example, the in-patient settings were described as a sensory overload:

> 'So you're overwhelming her senses with food, sensations in her stomach, noise, other people crying, high distress, so everything that's going to make an autistic person have a meltdown and behave in what they say is violent or unacceptable behaviour; that thrashing out meltdown, banging her head to calm herself, that only happens when the senses are overwhelmed and you're more likely to get that situation when you start treating an eating disorder.' (Carer 2)

Overall, carers frequently described themselves as feeling let down by current treatment options, to the extent that they felt forced to explore alternative treatments or provide treatments themselves at home. Many carers described attending courses, reading books and research papers in order to offer some level of treatment at home. Other carers described finding alternative sources of support, including personal trainers or private dieticians, to create a support system for their daughter that is not being offered in current treatment provisions.

'It was just better to just throw the book out of the window and go with my instinct.' (Carer 9)

Impact on carers

Carers described the impact that caring for their daughters had on their lives. A number of carers described having to leave their job, reducing their hours or working from home in order to better support their daughter. This was felt to have a negative impact on both their own well-being and mental health, and their relationships with their daughters.

'This is the hardest thing as a mum that I have ever had to deal with… I just don't know what to do. I feel like a complete failure as a mum, it is exhausting.' (Carer 10)

This is compounded with an apparent lack of specific support for carers from professional services. Although carers have positive comments about carer workshops and support, when they are offered, four carers (40%) mentioned the lack of specific support for autism comorbidity or comorbidities in general. Many carers also criticised the lack of post-diagnostic support for their daughters, describing how they were not able to access autism support services as their daughter did not have an intellectual disability (also known as learning disability in UK health services).

'They are all set up for what I would call, and I don't know what your typical patient with anorexia is like, but it is not our daughter; she has got complex needs and none of them, you know none of the workshops we attended addressed those extra needs.' (Carer 10)

All of this led to carers feeling frustrated and isolated from existing support systems. Instead, carers described setting up their own support groups and networks online, often on social media, as a way of supporting each other's specific needs. Furthermore, carers described having to self-advocate in order for their daughters to receive appropriate support and then sharing advice on how to go about this on social network groups.

'My heart breaks for the people and the non-help they are getting and when people start out on their journey and they are saying "I am not getting much help". I think wow, here we are eight to ten years later and we are still not getting any help at all. Everything that we have had to do I have had to fight for, and I do, and I will because you do, it is your child.' (Carer 1, describing her experience of online social media groups)

Improvement

All carers suggested various ways that services could be more friendly for patients with autism. For example, accommodating sensory difficulties by reducing the noise levels down in services by having soft-close doors and being mindful about clinicians shouting across corridors. Furthermore, carers felt that services could be flexible with treatment provisions to accommodate autistic traits, for example, adapting the diet plan to account for sensory difficulties with various food options.

'There are a few things, particularly noises are a big issue and I would also say that lighting is a big issue as well. When she goes to her meetings with the eating disorder nurse, when they switch the light on it causes her real problems.' (Carer 6)

The majority of carers (90%) advocated an increase in clinician awareness and knowledge of autism. Several carers described how their daughter had encountered specific clinicians during treatment who had knowledge of autism, and who were able to make adaptations. This was felt to be instrumental in building a rapport with their daughter and providing good care. However, these stories were limited to specific individuals, rather than representing systematic awareness and adaptations across wider treatment teams and hospital settings.

'It probably is just about education, is it not? … They are treating it purely as an eating disorder, and I think, I do not know, there needs to be some additional support, I do not think there is a full understanding.' (Carer 6)

Another important consideration that was mentioned by six carers (60%) was the importance of building a rapport with the individual before expecting them to do any difficult psychological work. A few suggestions were to have the first session doing a joint activity or playing a game, in order to build trust. One positive attribute that was mentioned in a number of the interviews was that the clinicians who took the time to build a rapport made a significant impact in the treatment their daughters received.

'Building a relationship with her, maybe not in the clinic, before expecting her to go to the clinic and be weighed. So, whether that was by email or by a letter or by asking her if she had any questions, she wanted to ask them but to do it on paper. All of that would have made it easier.' (Carer 4)

Discussion

At present, there is limited knowledge about how to provide the best clinical care for people with autism who have anorexia nervosa. The goal of this study was to explore carer views on how this can be achieved, while triangulating these findings with previous research on the views of clinicians and patients.[21,22] All carers interviewed felt that autism played a significant role in the development and maintenance of their daughters' anorexia nervosa. However, they commonly perceived that this comorbidity was not appropriately addressed in current treatment provision. This was described as part of a wider problem with available services: participants described several difficulties with service provision, including problems getting an autism diagnosis, and the perception that eating disorder services did not accept or adapt around the condition. This resulted in feelings of frustration and isolation for families, a scenario exacerbated by a perceived lack of support or specific resources for the carers of people with autism. Although interventions and support for people caring for someone with an eating disorder do exist, to date there is no specific support around caring for people with autism who have eating disorders.[27] In the context of these issues, participants made several recommendations for future improvements and changes.

There are many overlapping themes with interviews previously conducted with people with autism who have anorexia nervosa, and clinicians working in this field.[21,22] First, all qualitative studies with the main stakeholders identified that there are similarities in the features of both anorexia nervosa and autism, but that the underlying reason for these features might be different. For example, food restriction may be related to sensory sensitivities as well as concerns around weight gain. Furthermore, clinician, carer and patient interviews all highlight the sensory difficulties that people with autism face in current treatment settings that are largely overstimulating and require adaptation.[28]

Another overlapping theme was the need for longer treatment and interventions in order to build a rapport with the individual, and to improve treatment adherence, engagement and outcomes. This reflects previous recommendations from research on improving cognitive–behavioural therapy outcomes for people with autism who have depression, anxiety or OCD.[29] Significantly, this contrasts with the current climate of shorter in-patient admissions for patients with eating disorders as recommended by NICE

guidelines.[20] Clinical services will need to weigh up the potential benefits and improvements in outcomes with longer admissions for those with both conditions, and the potentially increased risk of institutionalisation that might occur from detaching the individual from their usual support and social networks.

The importance of a flexible and individualised approach to treatment was highlighted in the present study and previous clinicians and patient interviews. A common theme across these studies relates to a lack of awareness and understanding of autism in women, and the role that autism can play in anorexia nervosa.[30] A lack of understanding might be hindering services ability to adapt and modify treatment programmes effectively to cater for the individual needs of these patients. The study findings fits in with previous literature that has found that the needs of women with autism are not being met in current mental health services.[28,31,32] Future research should investigate how best to improve clinician awareness and knowledge in this area, in order to facilitate a more flexible approach to current treatment provision. A key area of service provision not meeting the needs of women with autism appears to be that of accessing an autism diagnosis. While this was highlighted by carers in the current study, previous research with clinicians working in eating disorder treatment settings suggest that there is no clear pathway for eating disorder clinicians to refer their patients for an autism assessment.[21] An additional barrier may relate to whether current assessments are appropriate for women. Recent research suggests that the Autism Diagnostic Observation Schedule may work well in identifying potential high autistic traits in women with anorexia nervosa.[9] Future studies on diagnostic tools for autism in women could benefit clinicians working in the eating disorder field.

Strengths and limitations

One limitation with the present study is that 9/10 of the participants were mothers. This may reflect the fact that women are more likely than men to provide care for family members with mental health difficulties.[33] Additionally, all carers in the study were providing care for their daughter with anorexia nervosa. In treatment settings, women with anorexia nervosa outnumber men with a ratio of around 10:1.[34] Future research should explore the opinions of fathers and other caring roles, such as partners, to ensure that we have a holistic view of carers needs.

The study also has a number of strengths. This is the first qualitative study exploring carers views on autism and anorexia nervosa comorbidity. The sample for the study came from a large geographical area across the UK and one participant from the USA, which supports real practice evidence for assessing current treatment provisions in the UK. Further research would need to be undertaken before extrapolating these findings outside of the UK, particularly in healthcare settings with different models of care. Despite coming from all over the UK, the carer stories were largely similar, further supporting the validity of the findings. This study also raised new questions about the psychological well-being of families and the potential economic costs for society with many carers disclosing that they have stopped working or were working reduced hours in order to support their loved ones. From this preliminary research, it is clear that carers reported issues that could be more effectively addressed and have clear clinical and research implications. For example, in order to address the lack of specific support around this comorbidity, specific psychoeducation and resources could be developed to address the needs of both patients and families.

Clinical implications

The current study, combined with previous research in the field, indicates that people with autism who have anorexia nervosa may benefit from treatment adaptations. These suggestions require further evaluation and empirical research to establish their efficacy. Potential avenues for future research on adaptations in this area include the following.

(a) The provision of more intensive care.[35]
(b) Individual interventions rather than group work.[18,19,36]
(c) Allowing for longer treatment durations.[37]
(d) Training and supervision in working with people with autism for eating disorder clinicians, for example in adapting communicative styles (Kinnaird et al,[21,22] current study).
(e) Considering the role of autism in the eating disorder formulation (Kinnaird et al,[22] current study).
(f) Accommodating sensory difficulties in nutritional rehabilitation and in the wider treatment environment (Kinnaird et al,[21,22] current study).
(g) Provision of support for carers (current study).
(h) Establish clear pathways for individuals presenting with autistic traits, to be assessed for an autism diagnosis in a timely manner (Kinnaird et al,[21] current study).

Overall, a key theme identified across the current study and previous qualitative research in this area has been the importance of clinicians taking a flexible and individualised approach when working with this population.[21,22]

James Adamson, MSc, Department of Psychological Medicine, Kings College London, UK; **Emma Kinnaird**, BA, MSc, Department of Psychological Medicine, Kings College London, UK; **Danielle Clemson**, BSc, MA, RMN, National Eating Disorder Service, South London and Maudsley NHS Foundation Trust, UK; **Madeleine Oakley**, BA, MSc, Dip. Psych, Department of Psychological Medicine, Kings College London, UK; **Kate Tchanturia**, PhD, DClin, FAED, FBPS, FHEA, National Eating Disorder Service, South London and Maudsley NHS Foundation Trust, UK; and Department of Psychological Medicine, Kings College London, UK

Correspondence: Kate Tchanturia. Email: Kate.Tchanturia@kcl.ac.uk

First received 27 Aug 2019, final revision 4 Mar 2020, accepted 21 Apr 2020

Supplementary material

Supplementary material is available online at https://doi.org/10.1192/bjo.2020.36.

Data availability

Anonymised data is available upon request.

Acknowledgements

We thank all the participants for their time and for sharing their stories.

Author contributions

All authors designed and agreed on the interview schedule. J.A., E.K., M.O. and K.T. designed the research methodology and analysed the transcripts. J.A. interviewed all the participants. All authors contributed to the writing of the manuscript, final editing and agreed on the final version.

Funding

We would like to acknowledge the Health Foundation an independent charity committed to bring better healthcare for people in the UK (Ref: AIMS ID): 111547 and the Maudsley Charity for their support. Maudsley Charity is an independent NHS mental health charity that works in partnership with patients and families, clinical care teams and researchers at South London and Maudsley NHS Foundation Trust, the Institute of Psychiatry, Psychology and Neuroscience, Kings College London, and community organisations, with a common goal of improving mental health, to support innovation, research and service improvement. E.K. was supported by a Medical Research Council Doctoral Training Partnership studentship (MRV N013700/1).

Declaration of interest

None.

ICMJE forms are in the supplementary material, available online at https://doi.org/10.1192/bjo.2020.36.

References

1 Gillberg C. Are autism and anorexia nervosa related? *Br J Psychiatry* 1983; 142: 428–.

2 Rothery DJ, Garden GMF. Anorexia Nervosa and Infantile Autism. *Br J Psychiatry* 1988; 153: 714–.

3 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. American Psychiatric Association, 2013.

4 Raevuori A, Keski-Rahkonen A, Hoek HW. A review of eating disorders in males. *Curr Opin Psychiatry* 2014; 27: 426–30.

5 *Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network; 14 Sites, United States, 2008*. Centers for Disease Control and Prevention, 2008 (https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm [cited 15 Aug 2019]).

6 Nicholls DE, Lynn R, Viner RM. Childhood eating disorders: British national surveillance study. *Br J Psychiatry* 2011; 198: 295–301.

7 Brugha TS, Spiers N, Bankart J, Cooper S-A, McManus S, Scott FJ, et al. Epidemiology of autism in adults across age groups and ability levels. *Br J Psychiatry* 2016; 209: 498–503.

8 Gould J, Ashton-Smith J. Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Pract* 2011; 12: 34–41.

9 Sedgewick F, Kerr-Gaffney J, Leppanen J, Tchanturia K. Anorexia nervosa, autism, and the ADOS: How appropriate is the new algorithm in identifying cases? *Front Psychiatry* 2019; 10: 507.

10 Milner V, McIntosh H, Colvert E, Happé F. A qualitative exploration of the female experience of autism spectrum disorder (ASD). *J Autism Dev Disord* 2019; 49: 2389–402.

11 Westwood H, Stahl D, Mandy W, Tchanturia K. The set-shifting profiles of anorexia nervosa and autism spectrum disorder using the Wisconsin Card Sorting Test: a systematic review and meta-analysis. *Psychol Med* 2016; 46: 1809–27.

12 Huke V, Turk J, Saeidi S, Kent A, Morgan JF. The clinical implications of high levels of autism spectrum disorder features in anorexia nervosa: a pilot study. *Eur Eat Disord Rev* 2014; 22: 116–21.

13 Westwood H, Eisler I, Mandy W, Leppanen J, Treasure J, Tchanturia K. Using the Autism-Spectrum Quotient to measure autistic traits in anorexia nervosa: a systematic review and meta-analysis. *J Autism Dev Disord* 2016; 46: 964–77.

14 Westwood H, Tchanturia K. Autism spectrum disorder in anorexia nervosa: an updated literature review. *Curr Psychiatry Rep* 2017; 19: 41.

15 Baron-Cohen S, Jaffa T, Davies S, Auyeung B, Allison C, Wheelwright S. Do girls with anorexia nervosa have elevated autistic traits? *Mol Autism* 2013; 4: 24–.

16 Tchanturia K, Adamson J, Leppanen J, Westwood H. Characteristics of autism spectrum disorder in anorexia nervosa: a naturalistic study in an inpatient treatment programme. *Autism* 2019; 23: 123–30.

17 Nielsen S, Anckarsäter H, Gillberg C, Gillberg C, Råstam M, Wentz E. Effects of autism spectrum disorders on outcome in teenage-onset anorexia nervosa evaluated by the Morgan-Russell outcome assessment schedule: a controlled community-based study. *Mol Autism* 2015; 6: 14–.

18 Tchanturia K, Larsson E, Adamson J. How anorexia nervosa patients with high and low autistic traits respond to group cognitive remediation therapy. *BMC Psychiatry* 2016; 16: 334–.

19 Adamson J, Leppanen J, Murin M, Tchanturia K. Effectiveness of emotional skills training for patients with anorexia nervosa with autistic symptoms in group and individual format. *Eur Eat Disord Rev* 2018; 26: 367–75.

20 National Institute for Health and Care Excellence. *Eating Disorders: Recognition and Treatment. Guidance and Guidelines*. NICE, 2017 (https://www.nice.org.uk/guidance/ng69/chapter/Recommendations#treating-anorexia-nervosa [cited 15 Aug 2019]).

21 Kinnaird E, Norton C, Tchanturia K. Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study. *BMC Psychiatry* 2017; 17: 292–.

22 Kinnaird E, Norton C, Stewart C, Tchanturia K. Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment? *Int Rev Psychiatry* 2019; 31: 308–17.

23 Highet N, Thompson M, King RM. The experience of living with a person with an eating disorder: the impact on the carers. *Eat Disord* 2003; 11: 327–44.

24 Sepulveda AR, Lopez C, Todd G, Whitaker W, Treasure J. An examination of the impact of "the Maudsley eating disorder collaborative care skills workshops" on the well being of carers. *Soc Psychiatry Psychiatr Epidemiol* 2008; 43: 584–91.

25 Brett D, Warnell F, McConachie H, Parr JR. Factors affecting age at ASD diagnosis in UK: No evidence that diagnosis age has decreased between 2004 and 2014. *J Autism Dev Disord* 2016; 46: 1974–84.

26 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.

27 Hibbs R, Rhind C, Leppanen J, Treasure J. Interventions for caregivers of someone with an eating disorder: a meta-analysis. *Int J Eat Disord* 2015; 48: 349–61.

28 Tint A, Weiss JA, Lunsky Y. Identifying the clinical needs and patterns of health service use of adolescent girls and women with autism spectrum disorder. *Autism Res* 2017; 10: 1558–66.

29 Spain D, Sin J, Chalder T, Murphy D, Happé F. Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: a review. *Res Autism Spectr Disord* 2015; 9: 151–62.

30 Bruder MB, Kerins G, Mazzarella C, Sims J, Stein N. Brief report: the medical care of adults with autism spectrum disorders: identifying the needs. *J Autism Dev Disord* 2012; 42: 2498–504.

31 Tint A, Weiss JA. A qualitative study of the service experiences of women with autism spectrum disorder. *Autism* 2018; 22: 928–37.

32 Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair WC, Ashkenazy E, et al. Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *J Gen Intern Med* 2013; 28: 761–9.

33 Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family - caregivers of people with mental illnesses. *World J Psychiatr* 2016; 6: 7–17.

34 Striegel-Moore RH, Leslie D, Petrill SA, Garvin V, Rosenheck RA. One-year use and cost of inpatient and outpatient services among female and male patients with an eating disorder: evidence from a national database of health insurance claims. *Int J Eat Disord* 2000; 27: 318–9.

35 Nazar BP, Peynenburg V, Rhind C, Hibbs R, Schmidt U, Gowers S, et al. An examination of the clinical outcomes of adolescents and young adults with broad autism spectrum traits and autism spectrum disorder and anorexia nervosa: a multi centre study. *Int J Eat Disord* 2018; 51: 174–9.

36 Dandil Y, Smith K, Adamson J, Tchanturia K. Individual cognitive remediation therapy benefits for patients with anorexia nervosa and high autistic features. *Eur Eat Disord Rev* 2019; 28: 87–91.

37 Stewart CS, McEwen FS, Konstantellou A, Eisler I, Simic M. Impact of ASD traits on treatment outcomes of eating disorders in girls. *Eur Eat Disord Rev* 2017; 25: 123–8.

Chapter 8: Eating as an autistic adult: An exploratory qualitative study

Kinnaird, E., Norton, C., Pimblett, C., Stewart, C., & Tchanturia, K. (2019c). Eating as an autistic adult: An exploratory qualitative study. *PloS One, 14*(8), e0221937. doi:10.1371/journal.pone.0221937

PLOS ONE

RESEARCH ARTICLE

Eating as an autistic adult: An exploratory qualitative study

Emma Kinnaird[1], **Caroline Norton**[2], **Caroline Pimblett**[2], **Catherine Stewart**[2], **Kate Tchanturia**[1,2,3]*

1 Institute of Psychiatry, Psychology and Neuroscience, Kings College London, London, United Kingdom, 2 South London and Maudsley NHS Foundation Trust, London, United Kingdom, 3 Ilia State University, Tbilisi, Georgia

* Kate.tchanturia@kcl.ac.uk

OPEN ACCESS

Citation: Kinnaird E, Norton C, Pimblett C, Stewart C, Tchanturia K (2019) Eating as an autistic adult: An exploratory qualitative study. PLoS ONE 14(8): e0221937. https://doi.org/10.1371/journal.pone.0221937

Editor: Jason R. Tregellas, University of Colorado Denver School of Medicine, UNITED STATES

Received: January 9, 2019

Accepted: August 19, 2019

Published: August 29, 2019

Data Availability Statement: Data cannot be shared publicly as participants did not give consent for their transcripts to be shared in the public domain. Data are available from the South London and Maudsley NHS Trust Ethics Committee and Clinical Governance Board (contact via slam-loppn.research@kcl.ac.uk) for researchers who meet the criteria for access to confidential data.

Funding: EK received PhD funding for this project through the Medical Research Council Doctoral Training Partnership (MRC DTP) scheme (MR/ND13700/1). KT would like to acknowledge support

Abstract

Background

Although eating difficulties are known to be common in children on the autism spectrum, there is a lack of research on whether these behaviours persist or change into adulthood. Emerging evidence suggests that autistic adults may experience higher levels of disordered eating than the general population, indicating the impact of autism on eating in this adult population warrants further exploration.

Method

This study interviewed 12 autistic adults about their eating habits, with a focus on the continuing or changing presence of behaviours often seen in autistic children such as sensory sensitivity or a preference for routines. Interviews were transcribed and analysed using thematic analysis.

Results

Overall, participants suggested that autism did continue to impact their eating into adulthood, particularly in the areas of sensory sensitivity, medical difficulties, executive functioning difficulties, and rigidity, but that they had learned to adapt so that these issues no longer represented a problem. However, a minority of participants did feel that their autism had a negative effect on their eating, particularly those diagnosed with eating disorders. Additionally, eating behaviours associated with autism were identified as potentially contributing to having an unhealthy body weight.

Conclusions

Certain traits associated with autism, such as cognitive rigidity and sensory sensitivity, could potentially continue to influence the eating behaviours of autistic adults. These traits are typically experienced as differences which can be adapted around and managed, rather than specific problems. However, these traits can potentially contribute to difficulties such as

from MRC and MRF Child and Young Adult Mental Health (MRVR004595/1) and support by the Health Foundation, an independent charity committed to bringing better health care for people in the UK. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: The authors have declared that no competing interests exist.

disordered eating and weight gain, and the implications of these should be explored by future research.

Introduction

The link between selective eating and autism in children is well-established in the research literature [1–3]. Children on the autism spectrum are more likely to have a restricted diet, refusing more foods and eating a more limited food repertoire than their typically developing peers [4–6]. This selectivity appears to be motivated by a number of factors. Studies suggest that children who exhibit higher levels of sensory sensitivity are more likely to refuse foods on the basis of sensory qualities, including texture, temperature, taste and smell [7]. Atypical sensory processing is common in autism [8], and selective eating in autism is associated with sensory sensitivity [1, 4, 9, 10]. The preference for routine, and behavioural inflexibility, associated with autism may also cause problems with eating, making children reluctant to try new foods or leading to the development of specific mealtime routines [4, 9, 11]. Eating problems may also be driven by physical difficulties associated with autism, such as motor problems (including chewing, or using utensils) or gastrointestinal symptoms [2, 12, 13]. Furthermore, the diets of children on the autistic spectrum may be deliberately restricted by parents- for example, gluten- or casein-free diets- with the goal of improving gastro-intestinal symptoms, or changing behaviour [14].

The nutritional impact of these restricted eating behaviours is less clear. Whilst children on the spectrum eat a more limited diet, the findings of research suggest that this does not necessarily lead to overall insufficient nutritional intake [15–17]. Although these children may be at risk of under-consuming specific nutrients, including calcium, fibre, folic acid, Vitamins A, D, and E [17–20], research suggests that this population may also over-consume certain food types. For example, there is evidence that children on the autistic spectrum may be at greater risk of having their weight classified in the overweight or obese range, potentially due to eating a limited diet of carbohydrate rich foods [21, 22].

However, there is comparatively less research on whether these eating behaviours associated with autism extend into adulthood [23]. (Please note that identity first language (e.g. autistic adults) will be used to refer to this population. A study found that this style is generally preferred by autistic adults, and identity first language was used by all participants in their interviews [24]). Investigating eating in autism beyond young childhood, one study found that food selectivity in autism, defined as only eating certain foods, was less pronounced in older children and adolescents compared to younger children, suggesting that this phenomenon may change as children get older [6]. However, research does suggest that some of these eating behaviours do persist in autistic adults. Autistic adolescents and adults are more likely to be reluctant to try new foods and exhibit more food sensitivities compared to their neurotypical peers [25]. Similar behaviours were found in a study examining eating problems in autistic adults with intellectual disabilities [26]. This reflects research suggesting that autistic adults similarly experience atypical sensory processing, including impacting the ability to taste [27–30]. A recent questionnaire designed to measure eating problems in autistic adults based on a previous literature review (primarily using research on children) and author clinical experience identified a number of other difficulties that may be experienced by this population, including motor control, environmental aspects surrounding mealtimes including social pressures, difficulty judging hunger or satiety, routine-focused behaviours, and executive functioning problems [23, 31].

The issue of whether eating problems persist into adulthood for autistic people is significant for two key reasons. Firstly, interventions or support developed to support people on the autistic spectrum with eating are primarily targeted at young children and their parents, and may not be appropriate for autistic adults. This is especially important as the food experiences of autistic adults are likely to be different to those of children: for example, adults are more likely to be expected to choose and prepare their own food. This would make problems such as the refusal of food provided by other people less relevant, but may cause other difficulties, such as around the executive functioning skills required to plan, purchase and cook meals [32]. Secondly, atypical eating behaviours may have a negative impact on both physical and mental health: research suggests that autistic adults may be at a higher risk of being overweight [33]. Furthermore, research in the eating disorder (ED) field suggests that there may be an association between autism and EDs [34]. Consequently, the aim of this study was to use qualitative methods to explore whether autism may impact eating for some autistic individuals in adulthood, and how far this is perceived by these individuals as a problem.

Method

Participant recruitment

Participants who had previously responded to an online study entitled "Problematic Eating on the Autism Spectrum" and gave permission to be contacted regarding future research were invited to participate in the study. The online study had previously been advertised on social media (Twitter), and was open to both autistic and neurotypical adults with and without a history of eating problems. Participants were eligible if they were over 18, and if they self-reported an autism diagnosis. Participants were excluded if they were not sufficiently fluent in English to participate in an interview.

Procedure

The study received ethical approval from London-City and East Research Ethics Committee and South London (18/ LO/0050). A total of 50 individuals were contacted, and a researcher explained the purpose of the study. 38 individuals did not respond or declined to take part, leaving a total sample of 12. All participants provided written informed consent. Interviews were conducted by over video conferencing (e.g. Skype), over the phone, or over instant messenger, depending on participant preference. The participants had no prior relationship with the interviewer but were made aware that the interviewer was neurotypical rather than autistic. Interviews were semi-structured, using a topic guide exploring eating behaviours and aspects of eating known to be atypical in autism, such as sensory sensitivity and selectivity. Participants were first asked to self-report demographic information, including their age, current weight and height, any history of an ED, and if they were experiencing any medical conditions impacting their eating. Participants were then asked questions exploring the role of autism in their eating, such as "Do you think that your autism affects your eating?" and "What would you like medical professionals to know about eating and autism?". Participants with a current ED were additionally asked more targeted questions about their ED, including "How well do you feel that current understandings of your ED apply to you and your experiences?" and "How do you understanding ED recovery in the context of your autism?". The interviewer was free to ask follow-up questions in response to topics raised by the participant. Each interview lasted between 20–45 minutes and was audio-recorded, with field notes made during each interview. No repeat interviews were carried out, and transcripts were not returned to participants. As this sample represented all eligible individuals who gave consent to participate from the initial online study, data saturation was not discussed.

Analysis

The study is presented in line with Consolidated criteria for reporting qualitative studies (COREQ) guidelines [35]. Data was analysed using thematic analysis [36]. Transcripts were read and reread by authors EK and KT to ensure familiarisation. An initial set of codes were then produced by EK based on the content of the transcripts, evaluated by KT, and applied to the data using NVivo 11 software. Coded data was then analysed to identify potential themes. These themes were then reviewed by EK and KT, evaluating how well they captured the coded data, and how far they reflected the entire data set. Responses to interview questions were highly heterogenous, reflecting the diversity of food experiences and attitudes endorsed by participants. However, within the responses, some unifying themes were identified: Autism and Eating, Impact, and Coping and Adapting. These were divided into sub-themes and are presented below.

Results

Participants

The final sample consisted of 12 participants: 2 men, 8 women, and 2 participants who identified as non-binary. Demographic information is summarised in Table 1. Participants were a mean age of 38.50 years ($SD = 13.87$), with a mean body mass index (BMI) of 25.61 ($SD = 8.10$). 2 participants did not report their exact weight and height, and instead reported their BMI category (e.g. underweight). 4 participants had a BMI defined as underweight, 2 had a BMI in the normal range, 3 had a BMI defined in the overweight range, and 3 had a BMI defined as obese. 6 participants self-reported experiencing an ED in their lifetime ($n = 4$ anorexia nervosa, AN; $n = 1$ bulimia nervosa; BN, $n = 1$ binge eating disorder; BED).

Unifying theme: Autism and eating

While not all participants described having difficulties with eating, they did feel that autism had some kind of impact on their eating. All participants described a degree of selectivity

Table 1. Participant demographic characteristics.

Participant	Gender	Age (years)	BMI Category	Age of autism diagnosis (years)	Medical conditions	Eating disorder history
1	Male	23	Overweight	4	Excoriation disorder, trichotillomania, anxiety	Binge eating disorder (current, 3 year duration)
2	Female	46	Normal weight	35		Anorexia nervosa (not formally diagnosed, recovered)
3	Female	41	Normal weight	37	Gluten intolerant	
4	Non-binary	39	Obese	38	Gastrointestinal problems	
5	Female	49	Overweight	48	Egg allergy, migraines	
6	Female	38	Obese	37	Anxiety, obsessive-compulsive disorder, cleft palate	
7	Male	71	Obese	49		
8	Female	49	Overweight	41	Lactose intolerant, food allergies	
9	Female	19	Underweight	15	Anxiety, dysthymic disorder	Bulimia nervosa (recovered)
10	Non-binary	31	Underweight	28	Bipolar disorder, post-traumatic stress disorder, obsessive-compulsive disorder	Anorexia nervosa (current, 4 year duration)
11	Female	34	Underweight	28		Anorexia nervosa (current, 34 year duration)
12	Female	22	Underweight	20		Anorexia nervosa (current, 1 year duration)

https://doi.org/10.1371/journal.pone.0221937.t001

around their eating and food choices: this included avoiding certain foods and eating from only a specific range of food or meals. Autism was also felt to impact their eating in other ways, including leading to difficulties with aspects such as cooking and eating in communal environments. A number of factors associated with participants' autism were found to contribute towards these behaviours, which are presented below as sub-themes.

Sub-theme: Medical issues. A number of participants described having medical problems which affected their eating, typically through motivating them to avoid certain foods or environments. The most common of these were food allergies, leading participants to avoid specific foods. Similarly, one participant who experienced migraines described avoiding certain foods to avoid triggering the condition. Two participants experienced gastrointestinal problems, which again led them to alter their diets by eliminating certain foods, or eating more of foods with a beneficial effect. A further two participants had difficulties with physical coordination, which led them to avoid communal eating environments due to difficulty using cutlery, or fear of social embarrassment. One participant felt that their mental health conditions and associated medication led them to eat less due to stomach discomfort, and one participant avoided communal, loud eating environments due to medical hearing problems making the experience unpleasant.

Sub-theme: Sensitivity. Participants described avoiding certain foods, or in one case seeking out specific foods, in order to manage their sensory input. For some, this was avoiding certain foods due to hypersensitivities to aspects like taste, texture, smell, and temperature. While some participants described this in terms of dislikes- "if the texture is off, that food can be just fantastic and I'll still loathe it" (Participant 4), for others this sensitivity was so extreme it caused pain, gagging, or a "meltdown" (Participant 9). While most participants described aversion to specific sensory experiences, such as certain textures, one participant actively used food to increase their sensory stimulation by actively seeking out strong flavours.

Hypersensitivity to certain sensory stimuli also motivated participants to avoid or alter their eating environments. A common experience was avoiding loud environments due to hypersensitivity to noise, which often led to participants avoiding communal eating areas such as restaurants or school dining halls:

> "I'd rather not eat in a loud restaurant or dining hall, or just anywhere where I can't talk to people next to me or just have some peace and quiet. . . if I'm in an environment where there's lots of background noise, I find it hard to filter out the background noise. And I think, because I've always been good at music, I'm very sensitive to variations in sound" (Participant 2).

These environmental sensitivities meant that participants required a degree of control around their eating environments. Where this kind of control was not available, this sometimes led to avoiding eating in that environment completely:

> "I don't like the smell sometimes that forks and knives have on them. So I will insist on clean cutlery, and if it smells peculiar I will send it back and get clean ones. And in fact sometimes mugs out of the dishwasher have that smell in them as well, and I don't know what that smell is but it's pungent. And so if it doesn't smell just right I won't eat out of it or on it" (Participant 5).

Participants additionally felt that their eating behaviours were influenced by a difficulty in identifying internal sensations, or interoception- specifically, problems identifying if they were hungry or full. This was viewed by one participant as being closely related to stress levels, and

was felt to contribute to under-eating- "it's the immediate feeling of being full. You know, two bites and you're full, that's it. Even if you were a bit hungry, two bites and you're done" (Participant 3).

Sub-theme: Executive functioning. Difficulties with executive functioning also impacted some participants' eating habits. Problems with aspects such as planning and memory made it difficult to acquire food, with participants describing issues with food shopping, cooking and food preparation, and ordering food. At worst, this led to not eating at all:

> "Planning and doing things in the right order can be a big barrier to accessing food. for example, I don't leave my room unless I have a visual mental plan of exactly what I'm going to get, where it is, and how I'm going to get it (often with a backup plan or two so that I don't panic if my first plan is disturbed), and if I don't come up with a satisfactory plan I just don't go at all. Doing things in the right order can be difficult if anything isn't according to plan, like if I drop something or someone tries to talk to me—it's as if once I start executing a plan I enter a sort of autopilot mode, and the system gets lost if it's bumped off course. Oftentimes when that happens I quickly give up and pick something at random to get out as quickly as possible, and that can result in accidentally picking something sensory-bad" (Participant 9).

Consequently, accessing food was viewed by some as requiring a large amount of mental energy and preparation. When participants were distracted or preoccupied by other things, such as stress, this limited the amount of mental energy they could devote to food and eating, again leading to not eating. This appeared to be linked to difficulties with interoception, or having the executive capacity to mentally register the sensation of hunger: "literally forgetting to eat because I just get too busy to, I don't know, recognise the signals" (Participant 3).

Sub-theme: Rigidity and routines. As well as avoiding certain foods, another key behaviour described by participants was that of eating similar foods repeatedly (described by Participant 10 as "samefooding"), or forming a specific routine around eating. This appeared to be related to the mental tendency towards rigidity and routines associated with autism: "you're quite rigid, you're quite kind of control orientated, you're quite kind of perfectionist" (Participant 10).

For a number of participants, food was viewed as a key aspect of life that they could control. This led to repetitive and routine-based eating habits, including a preference for familiar foods and an aversion to trying new things. However, the importance of these routines varied across participants: some described their routines as a preference which could be broken without distress, whereas others were more rigid in their behaviours. For one participant, this rigidity was in part motivated by a fixation on information and numbers. They described finding comfort in their BMI always being at the exact centre of the "healthy" spectrum, and always reading food labels: "I think I'm in control of everything simply because I'm in control of the facts, and I know exactly why I'm doing what I'm doing" (Participant 3).

Rigid thinking patterns also contributed towards eating habits, in particular categorical thinking styles creating aversions towards certain foods. Several participants described having one bad experience with a specific food- for example it causing food poisoning- and not eating that food again: "The milk was sour at school once, and I wouldn't drink milk for a long time after" (Participant 7). For a small number of participants, this rigidity manifested as a compulsion towards meal completion, regardless of hunger. Alternatively, other participants felt their rigid thinking styles led them to restrict or avoid food. Trying to break these routines or rigid thought patterns was seen as requiring mental effort, "[It is] easier if I don't have to think about something new to eat. If I know something is good, and that, you know, I'll feel ok after eating it, then I'm likely to eat it again" (Participant 8).

Unifying theme: Impact

Although all participants felt that autism influenced their eating to some degree, the impact they felt this had on their lives varied significantly across the sample. The majority of participants did not see their eating behaviours as a problem, but rather a part of their lives which could be managed. However, the participants who had experienced diagnosed EDs did identify the influence of autism on their eating as a significant issue. All participants interviewed in the sample felt that they were still able to get their nutritional needs from the food that they ate, or that they were able to manage any deficiencies with supplements.

Sub-theme: Social. Participants identified their behaviours around food as impacting how they behaved in social situations involving eating. This was particularly pronounced around communal eating spaces: firstly, an aversion to certain environments—such as the noise associated with communal spaces like restaurants- prevented or made participants reluctant to attend social events in these locations. Difficulties around eating in communal spaces was related to participants' abilities to manage their routines and preferences around food, which was made more difficult in social situations. Eating with other people meant that they could not control or avoid experiences or behaviours that they found aversive: for example, if they found overeating distasteful they could not prevent other people overeating, leading to feelings of awkwardness or isolation:

> "How do people eat like that? I don't get it. But I don't want to eat like that so you know, I don't feel inspired. I feel a bit repulsed actually, just sit back and observe in grotesque curiosity I suppose" (Participant 3).

Similarly, eating with other people meant that individuals could not always control or select the food being eaten, particularly in the case of family meals eaten at home. Where the food was not palatable or was particularly sensory aversive, participants described eating separately to their family.

As well as being highly aware and sensitive to the behaviours of people around them, some participants were concerned that the people around them would be similarly aware of their own behaviours. These described feeling self-conscious or embarrassed around their own eating habits or difficulties in front of others, leading them to eat alone or only with close acquaintances. For one participant, this aversion to eating in social situations was related to viewing eating food as a purely functional requirement, rather than a pleasurable experience:

> "When given the choice, I always prefer to eat alone rather than with people. Eating is not about "hanging out", it's about "putting food in my belly so it stops complaining". There's an element of social anxiety to that, what if I spill food on my shirt. . . I am self-conscious about the things I am because they're things *I* would be self-conscious about if someone did them around me" (Participant 4).

However, the majority of other participants described still finding enjoyment in eating with other people. Participants generally described preferring, and enjoying, eating with smaller social groups in quieter settings, and so did not experience avoiding busier social environments such as restaurants as a problem.

Sub-theme: Weight and eating disorders. Only 2 participants in the sample reported having a BMI in the defined "normal" weight range: all other participants were classified as being in either the under- ($n = 4$) or the overweight/obese ($n = 6$) range. All participants with a BMI in the underweight range either had a current ED diagnosis, or a history of EDs. The

overweight participants did not identify their weight as a problem: only one participant, who had previously been overweight but lost weight, saw being overweight as a significant problem in their life. Apart from this participant and individuals with diagnosed EDs, no other participant felt that their eating behaviours caused any physical or health problems.

Both individuals in both the under- and overweight ranges exhibited similar underlying behaviours, but with different effects. For example, both groups described experiencing rigidity around their eating. For those who were underweight this rigidity appeared to contribute towards restriction, or eating only low calorie foods, leading to weight loss. For those who were overweight, this rigidity and repetitiveness tended to be focused around high calorie foods, leading to weight gain:

> "I think that sometimes I find that I've gotten into a rut with the same thing over and over, and if its something like- something high calorie like chocolate for instance, I struggled with that. Because I started eating it at a certain time of day and then I kept doing that for a long time and I was gaining weight and I noticed that I was constipated and I had to stop that habit. But it's very easy for me to get into a habit" (Participant 8).

Similarly, both groups described rigid thinking styles that alternatively contributed to under- or overeating. For some, previous experiences had led them to develop a strong compulsion towards completing meals, eating quickly, or over-eating, which they now found difficult to break. Where participants were exposed to certain behaviours or models around eating or body image around childhood, they found these persisted into adulthood and were difficult to break:

> "If you're not taught how to eat well, and you know the sort of behaviours you see as a child is emotional comfort eating, I guarantee you that's what my mum does. Then that's the sort of thing you're exposed to, you know, having a bowl of cereal sized for six people before you go to bed sort of thing, or you know, asking for a bowl of ice cream and you get the entire tub before you go to bed, just because somebody's upset you you eat a candy bar. You know, that sort of thing, if that's what you've been exposed to, which I was, then that, the sort of patterns that you assume" (Participant 3).

This participant further suggested that the rigid thinking styles associated with autism may make autistic people particularly vulnerable to these kind of environmental influences, especially in childhood:

> "We're all so literal, and all these messages that are out there and all these skinny girls on Instagram- now it's the bodybuilders on Instagram, you know, the fitness freaks on Instagram. . . I think these things are all around us, I think we've got to think about them very clearly and carefully. Particularly when we're thinking about how literal autistic people take these messages" (Participant 3).

These experiences therefore led to the formation of certain attitudes or behaviours around food which, combined with the rigidity associated with autism, proved difficult to challenge. For some individuals, this led to under- or overeating, to the degree that their body weight was classified medically as unhealthy, or the development of EDs:

> "Autistic people often misuse "black and white thinking", and I know that affects what and when I eat at home, because if I go to get a snack and my mom says it's too sugary or it's

saved for something/someone else, I don't get a different snack, I just don't eat. I think that sort of thing contributed to my eating disorder at the start" (Participant 9).

Across the sample, the participants who identified autism as having the biggest impact on their eating were typically those diagnosed with EDs, although the aspects of autism they felt influenced their eating (such as rigidity) were highly similar to those without EDs. Out of the 12 participants interviewed, 6 reported having experienced an ED in their lifetime: 4 participants had experienced AN, 1 had been treated for BN, and 1 was undergoing treatment for BED. The motivating behaviours underlying their symptoms were highly similar, and strongly overlap, with those seen with those contributing to under- and overeating, and subsequent weight loss or gain. For example, the participant with BED identified a strong compulsive element to their eating leading to overeating:

"I definitely have a tendency towards completion that will cause me to finish a meal that I am not necessarily hungry to finish, and that may be one thing about it. There's definitely a compulsive element to my eating a lot of times. I also think that, you know, there's an impulsive element to my eating, and they both sort of come together to, you know, create binge episodes when they do occur" (Participant 1).

Notably, participants with EDs did not typically describe their ED symptoms in terms of emotions, or as strongly influenced by body image. Rather, they strongly related their EDs to the impact of autism, including the role of thinking styles, or viewed it in a functional manner-for example, fulfilling their need for control. The participant with BED explicitly stated that they did not experience the negative emotions around food traditionally associated with binging; rather than binging to cope with negative emotions, they instead found their binging was impulsive and triggered by having access to food (Participant 1).

Unifying theme: Coping and adapting

The majority of participants described having difficulties with eating during their childhood. As they got older, they felt that they, and the people around them, had consciously worked to manage the influence of autism on their eating to the extent it no longer represented a problem: although all participants felt autism still impacted their eating, they were able to manage and adapt around this impact. Consequently, most participants did not perceive the influence of autism on eating as difficult or problematic.

Sub-theme: Progression from childhood. Participants generally described becoming more flexible around food as they became older, with one participant suggesting that their eating became more adventurous with "maturity and self-reflection" (Participant 1). Whilst some participants viewed this as happening gradually, without necessarily requiring conscious effort, others described this as an active process:

"For a long time I would eat only foods I recognized. I worked pretty hard to overcome that. . . and I have learned to like the experience of trying a new thing, even if it may not be what I know. . . they've improved because I worked at them" (Participant 4).

Specific changes included making an effort to try new foods, and therefore gradually reducing the associated anxiety associated with unfamiliar foods. Some participants felt that their eating improved from childhood due to support from their family in this process: one participant described how their parents used routines to help introduce new foods in a boundaried, safe way:

"I was raised with a rule that if we ate out at a buffet I had to pick one food I'd never tried before, before I was allowed to eat whatever else I wanted; and if we ate at home, I had to eat everything that was given to me (I literally spent hours sitting with my dinner, especially if it was squash or asparagus) but I was allowed to ask for a "no-thank-you portion," which is smaller. So I feel like that habit helped me diversify my tastes and it definitely gave me courage to try new things" (Participant 9).

By contrast, one participant felt that taking control of their own eating, separate to the habits they had been raised with as part of their family, was key to improving their eating habits and their attitude towards food. For this participant, self-education as an adult around diet and nutrition was key to this process:

"I think not knowing that my body weight was actually linked to how much I put down my neck- no one ever told me that the two were linked together- was just a big issue as well. So I think this has been a lifelong thing for me. Never knowing that the two were related, never knowing it was something that I had at least some degree of control, responsibility for. As a responsible adult. I think once I discovered that about five or six years ago and once I discovered that it was something that I could change and I did have some power over, then that was empowering in itself and that's when I started to take some control over it" (Participant 3).

Sub-theme: Coping as an adult. Participants commonly described one of the key ways they coped with the influence of autism on their eating as an adult as simply avoiding problem areas, and finding ways to cope around any potential difficulties. For example, one participant who ate a vegan diet due to their self-identified special interest in the environment and animals was careful to take food supplements and eat a balanced diet to ensure they received the necessary nutrition. Similarly, individuals who struggled to eat in restaurants would avoid these kind of locations, and where unavoidable would find ways to ameliorate this difficulty: for example, by asking their partner to order their food for them.

One key area of difficulty which participants described finding ways to adapt around was that of cooking. Cooking was commonly described as a difficult task, either due to executive functioning difficulties or due to sensory aversion to touching or preparing certain foods. Some participants described managing this by predominantly eating in preferred restaurants (where restaurants were not an environmental aversion), or by eating pre-prepared meals. Others used only familiar recipes which represented less of an executive functioning burden. Individuals with families described difficulties cooking as they sometimes were unable to eat the same meal as the rest of their family. One participant managed this by cooking all meals at the weekend, enabling them and their family to individually choose from a selection of meals during the week. Significantly, in the case of cooking and meal planning for the week, participants described using their tendency towards routine-based behaviour as a strength: they found that planning meals ahead of time helped both with cooking and eating, "making meal plans helps, I think, because I then kind of have to—I don't get into a panic about "oh, what should I eat". I've kind of got it all sorted out before" (Participant 11).

Sub-theme: Support from others. Participants also described support from family and friends as vital in managing their eating. This included having food prepared for them in a specific way, being encouraged to try new things, and being reminded to eat. Crucially, support was seen as most helpful where it respected their boundaries:

"They also know about my "nope" reflex. Some things just make me go "nope" and they don't chase me with them or ask me to try them anyway… We all abide by these boundaries and it helps tremendously" (Participant 3).

Sub-theme: Medical professionals. The only participants who had ever discussed their eating with a medical professional were those who had sought treatment for EDs. Of those who sought treatment, they found the experience most beneficial when the impact of their autism on their eating was acknowledged, considered and respected: "My experiences, be they atypical, are still perceived as valid" (Participant 1). However, participants felt that this required a knowledge of autism and its potential influence on eating that medical professionals may not have:

"I think it would be helpful if more professionals were aware of the sensory differences and the frequently-comorbid gastrointestinal issues that can make eating difficult for people with autism, as well as the same fooding phenomenon and other routines. Also, in general, they need to understand that meltdowns and sensory overload aren't tantrums or bad behaviour and can't be helped by treating them as such—especially with food, it's not as simple as being picky, it can range from unpleasant to uncomfortable to painful" (Participant 9).

Participants both with and without EDs strongly felt that medical professionals needed to view the influence of autism on their eating as intrinsic, rather than as a choice. They also emphasised that their eating should not be unnecessarily pathologized or seen as an illness:

"I think that would be the biggest thing I would want medical professionals to know, not necessarily for myself but for my youngest daughter. To know that there is a category of people who have these eating issues and they don't actually have anything to do with the shape of their body. And to tell them that they need to change is wrong. It's ethically wrong and it's going to ethically fail, it's going to cause these people more damage. It's not the best way to go about things" (Participant 3).

Where the individual was experiencing eating problems, participants felt that the best way to approach this would be using flexibility, and having knowledge of the difficulties commonly associated with autism and eating, whilst retaining awareness that different people will have different experiences.

Discussion

To date, the majority of research on eating on the autism spectrum has focused on children [1]. The experiences of participants in this study generally suggest that their eating behaviours improved from childhood into adulthood, resonating with previous research suggesting improvements throughout childhood [6]. Participants indicated they now ate a broader range of foods, and experienced less distress around eating, to the extent that they did not feel that their eating behaviours were problematic or represented a particular difficulty. However, the influence of autism on eating was felt to persist into adulthood: contributing factors documented in this study included sensory sensitivity [27, 28], persisting routine-based behaviours, and aversion to new foods. The key difference between childhood difficulties and adulthood differences suggested by this study was that participants had actively worked to cope with these core traits, either by deliberately challenging themselves (e.g. to try new foods), or

through adaptation (e.g. avoiding sensory-aversive foods). This reflects research that the adaptive skills of autistic people improve into adulthood, particularly in the domain of daily living [37].

However, adulthood did appear to raise new, life-stage specific difficulties surrounding eating. As participants in this study moved out of the childhood family environment and became more independent, this raised new problems- most notably, with cooking. Executive functioning difficulties are common in autism, and this study suggests that this may make cooking a difficult, off-putting task for some autistic people [32]. Ways of coping described in this study included using meal plans, becoming familiar and confident with specific recipes, using pre-prepared meals, and asking family to prepare food. The findings of this study suggest that some autistic adults may benefit from practical support with cooking- although there is a lack of research in this area, there is a suggestion that cooking skills may improve with structured instructions and information [38, 39]. A related issue raised by this study is that outside the structured environment of family mealtimes, some participants reported forgetting to eat. This was also linked to difficulties with interoception- specifically, detecting hunger or satiety, which is an area which is known to be atypical in autism [40]. Again, autistic people who experience these difficulties may benefit from structured meal plans to avoid reliance on hunger and satiety cues.

A strong finding from this study was that participants felt that their eating behaviours should not be unnecessarily pathologized: whilst they viewed autism as impacting their eating, participants had generally found ways to cope with this impact. For the majority of participants in this study, they viewed their eating habits as different, not problematic, and wanted medical professionals to sensitively acknowledge this difference rather than unnecessarily challenging their behaviours. Interventions or outside assistance was seen as most helpful where it helped participants adapt around their behaviours, or gradually explore them in a boundaried way, rather than aiming for fundamental change. However, in this wider context, half of participants had experienced problematic eating in the form of EDs. That participants in this study viewed their autism as contributing to their EDs resonates with previous research. There is a well-documented relationship between autism and AN: individuals with AN are more likely to be on the autistic spectrum compared to the general population [34, 41]. That this study suggests that autism may influence eating behaviours, and contribute to restriction, is in line with research on co-occurring autism and AN: a recent study interviewing autistic people with AN found that they strongly viewed autism as contributing to the disordered eating behaviours through the associated cognitive rigidity, sensory sensitivity, and executive functioning[42]. However, there is less research on autism and other EDs, particularly BED. That autism was perceived by participants in this study to be related to overeating suggests that there is a potential need for more research on autism and its relation to disordered eating behaviours beyond restriction.

The need to explore the relationship between autism and eating behaviours beyond restriction is emphasised by the finding that the majority of participants in this sample had a BMI defined in the overweight range. There was a divergence in this study between the perception of the majority of autistic participants, who viewed their eating behaviours as having no significant negative effects on their health, and the fact that the majority of these participants also had a weight defined in an unhealthy range. Weight problems are not unique to autistic people: the World Health Organisation (WHO) estimates that 39% of adults are overweight, and 13% are obese [43]. However, research does suggest that both adults and children on the autism spectrum may be at higher risk of being overweight, with one study finding that as many as 34% of autistic adults may have weights in the obese range [33]. This suggests that autism may be linked to eating behaviours that lead to excessive energy intake [22, 44, 45]. The

results of the present study suggest that the cognitive rigidity and routine-based behaviours associated with autism could contribute towards these eating behaviours: for example a compulsion towards completing meals, restricting one's diet to high calorie foods only, or having routines around repeatedly eating high calorie foods. Furthermore, atypical interoception could also add to these behaviours by making it difficult to identify satiety, leading to overeating [40].

However, the issues raised in this present study may indicate that traditional medical approaches to managing weight, typically aimed at neurotypical people, may not be as effective for autistic people. Participants in this study commonly viewed the aspects of autism that contributed towards their eating behaviours, such as sensory sensitivity, as intrinsic and unchangeable. These aspects may hinder traditional weight loss approaches: for example, attempts to limit caloric intake may be limited if the individual's diet is restricted to high calorie foods. Research into weight management programmes for children and youths on the autistic spectrum suggest that successful interventions involve individualisation, including tailoring of any dietary or behavioural recommendations to consider aspects such as sensory sensitivity [46]. However, further research is required for the adult population and in consultation with adults.

Limitations

This was a qualitative study intended to explore eating behaviours with autistic adults. Consequently, this study used a small sample size, and further research is required to establish whether these findings are generalisable to the wider autistic population. It is possible the recruitment approach- advertising the initial online study as exploring problematic eating in autism- may have led to a self-selecting sample already interested in autism and its potential contribution to eating problems. The final study sample also had a majority of female participants, whereas autism is a condition which predominantly affects men by a ratio of around 3:1 [47]. This could additionally limit generalisability to the wider autistic population. Furthermore, participant characteristics- including weight, autism diagnosis, and ED diagnosis, were all self-reported.

Notably, all participants interviewed in this study were able to verbally communicate, and the eating behaviours and difficulties raised by this population may be qualitatively different to other autistic populations, such as those with intellectual disabilities. For example, no participants in this sample reported pica (the compulsive and repetitive consumption of inedible or non-nutritive items), despite pica being observed in autistic individuals with intellectual disabilities [48]. A further limitation of this study was that, whilst focusing on eating behaviours, it did not explore the closely related issue of exercise and physical activity. Whilst the findings of this study give insight in the potential eating behaviours that may contribute towards excessive energy intake in autistic populations, research suggests that this may be exacerbated by autistic people being less physically active [49]. Further research into the heightened risk of being overweight in autistic people should explore exercise as a potential factor, as well as the eating behaviours raised in this current study.

Future research and clinical recommendations

Whilst the majority of participants in this study viewed the impact of their autism on their eating as a difference, some participants did feel that traits associated with their autism contributed towards difficulties with eating, including the development of EDs. That autistic adults may experience difficulties with their eating related to their autism is a topic currently underexplored in the research literature, and requires further attention. The majority of studies in

this small research area have focused on the relationship between autism and restrictive eating in AN [34]; whereas the findings of this study suggest that traits associated with autism (e.g. cognitive rigidity and repetitive behaviour) can also contribute to over-eating and weight gain.

In particular, there is a need for further research on the implications of these findings for clinical practice. Where autistic adult presents to medical services with eating difficulties or problems with weight management, the experiences of participants in this study strongly suggest that clinicians need to explore the potential role of autism in these issues. This could include sensory sensitivity, routinic behaviour, or difficulties with executive functioning. At present, there is one self-report questionnaire aimed at assessing these kind of eating and mealtime difficulties in autistic adults: the SWedish Eating Assessment for Autism spectrum disorders (SWEAA) [31]. The SWEAA yields information on a number of areas, including interoceptive problems, difficulties with social eating, issues with physical coordination, and disordered eating behaviours. More research is required to understand how this kind of information could be incorporated into specialised dietary interventions for this population. Alternatively, a key finding from this current study was that some autistic adults experience issues like sensory sensitivity or routinic behaviour as a difference, rather than a difficulty. Therefore, although clinicians may identify the presence of these kind of behaviours, they will likely need to explore with the autistic individual to what extent these represent difficulties that require treatment, or whether the behaviour should be accepted by the clinician as a difference which the person is content to live with.

Acknowledgments

The authors would like to thank the participants in this study for contributing their time and their experiences to this research.

Author Contributions

Conceptualization: Emma Kinnaird, Caroline Norton, Caroline Pimblett, Catherine Stewart, Kate Tchanturia.

Formal analysis: Emma Kinnaird, Kate Tchanturia.

Investigation: Emma Kinnaird.

Methodology: Caroline Norton, Kate Tchanturia.

Project administration: Caroline Norton, Caroline Pimblett.

Supervision: Catherine Stewart, Kate Tchanturia.

Writing – original draft: Emma Kinnaird.

Writing – review & editing: Emma Kinnaird, Catherine Stewart, Kate Tchanturia.

References

1. Cermak SA, Curtin C, Bandini LG. Food Selectivity and Sensory Sensitivity in Children with Autism Spectrum Disorders. Journal of the American Dietetic Association. 2010; 110(2):238–46. https://doi.org/10.1016/j.jada.2009.10.032 PubMed PMID: WOS:000276993700013. PMID: 20102851
2. Vissoker RE, Latzer Y, Gal E. Eating and feeding problems and gastrointestinal dysfunction in Autism Spectrum Disorders. Research in Autism Spectrum Disorders. 2015; 12:10–21. https://doi.org/10.1016/j.rasd.2014.12.010 PubMed PMID: WOS:000352925900002.
3. Marshall J, Hill RJ, Ziviani J, Dodrill P. Features of feeding difficulty in children with Autism Spectrum Disorder. International Journal of Speech-Language Pathology. 2014; 16(2):151–8. https://doi.org/10.3109/17549507.2013.808700 PubMed PMID: WOS:000333035000007. PMID: 24001171

4. Schreck KA, Williams K, Smith AF. A Comparison of Eating Behaviors Between Children with and Without Autism. Journal of Autism and Developmental Disorders. 2004; 34(4):433–8. https://doi.org/10.1023/b:jadd.0000037419.78531.86 PMID: 15449518
5. Bandini LG, Anderson SE, Curtin C, Cermak S, Evans EW, Scampini R, et al. Food selectivity in children with autism spectrum disorders and typically developing children. The Journal of pediatrics. 2010; 157(2):259–64. Epub 04/01. https://doi.org/10.1016/j.jpeds.2010.02.013 PMID: 20362301
6. Beighley JS, Matson JL, Rieske RD, Adams HL. Food selectivity in children with and without an autism spectrum disorder: Investigation of diagnosis and age. Research in Developmental Disabilities. 2013; 34(10):3497–503. https://doi.org/10.1016/j.ridd.2013.07.026 PubMed PMID: WOS:000324968500046. PMID: 23948127
7. Smith AM, Roux S, Naidoo NT, Venter DJL. Food choices of tactile defensive children. Nutrition. 2005; 21(1):14–9. doi: https://doi.org/10.1016/j.nut.2004.09.004. PMID: 15729777
8. Ben-Sasson A, Hen L, Russ R, Cermak SA, Engel-Yeger B, Gal E. A Meta-Analysis of Sensory Modulation Symptoms in Individuals with Autism Spectrum Disorders. Journal of Autism and Developmental Disorders. 2009; 39(1):1–11. https://doi.org/10.1007/s10803-008-0593-3 PubMed PMID: WOS:000261831800001. PMID: 18512135
9. Williams PG, Dalrymple N, Neal J. Eating habits of children with autism. Pediatric Nursing. 2000; 26 (3):259–64. PMID: 12026389
10. Schiffman SS. Influence of medications on taste and smell. World journal of otorhinolaryngology—head and neck surgery. 2018; 4(1):84–91. https://doi.org/10.1016/j.wjorl.2018.02.005 PMID: 30035266
11. Klein U, Nowak AJ. Characteristics of patients with Autistic Disorder (AD) presenting for dental treatment: a survey and chart review. Special Care in Dentistry. 1999; 19(5):200–7. https://doi.org/10.1111/j.1754-4505.1999.tb01386.x PMID: 10765886
12. McElhanon BO, McCracken C, Karpen S, Sharp WG. Gastrointestinal Symptoms in Autism Spectrum Disorder: A Meta-analysis. Pediatrics. 2014; 133(5):872–83. https://doi.org/10.1542/peds.2013-3995 PMID: 24777214
13. Green D, Charman T, Pickles A, Chandler S, Loucas T, Simonoff E, et al. Impairment in movement skills of children with autistic spectrum disorders. Developmental Medicine & Child Neurology. 2009; 51 (4):311–6. https://doi.org/10.1111/j.1469-8749.2008.03242.x PMID: 19207298
14. Dias EC, Rocha JS, Ferreira GB, Pena GD. Gluten-free and casein-free diet in autism spectrum disorder: a systematic review. Revista Cuidarte. 2018; 9(1):2059–73. https://doi.org/10.15649/cuidarte.v9i1.485 PubMed PMID: WOS:000437491400010.
15. Graf-Myles J, Farmer C, Thurm A, Royster C, Kahn P, Soskey L, et al. Dietary Adequacy of Children with Autism Compared with Controls and the Impact of Restricted Diet. Journal of Developmental and Behavioral Pediatrics. 2013; 34(7):449–59. PubMed PMID: WOS:000330359000001. https://doi.org/10.1097/DBP.0b013e3182a00d17 PMID: 24042076
16. Schmitt L, Heiss CJ, Campbell EE. A Comparison of Nutrient Intake and Eating Behaviors of Boys With and Without Autism. Topics in clinical nutrition. 2008; 23(1):23–31.
17. Hyman SL, Stewart PA, Schmidt B, Cain U, Lemcke N, Foley JT, et al. Nutrient Intake From Food in Children With Autism. Pediatrics. 2012; 130:S145–S53. https://doi.org/10.1542/peds.2012-0900L PubMed PMID: WOS:000209485500012. PMID: 23118245
18. Sharp WG, Postorino V, McCracken CE, Berry RC, Criado KK, Burrell TL, et al. Dietary Intake, Nutrient Status, and Growth Parameters in Children with Autism Spectrum Disorder and Severe Food Selectivity: An Electronic Medical Record Review. Journal of the Academy of Nutrition and Dietetics. 2018; 118 (10):1943–50. https://doi.org/10.1016/j.jand.2018.05.005 PubMed PMID: WOS:000445432100012. PMID: 30005820
19. Bamhill K, Gutierrez A, Ghossainy M, Marediya Z, Devlin M, Sachdev P, et al. Dietary status and nutrient intake of children with autism spectrum disorder: A case-control study. Research in Autism Spectrum Disorders. 2018; 50:51–9. https://doi.org/10.1016/j.rasd.2018.03.002 PubMed PMID: WOS:000431095700006.
20. Mari-Bauset S, Llopis-Gonzalez A, Zazpe I, Mari-Sanchis A, Suarez-Varela MM. Comparison of nutritional status between children with autism spectrum disorder and typically developing children in the Mediterranean Region (Valencia, Spain). Autism. 2017; 21(3):310–22. https://doi.org/10.1177/1362361316636976 PubMed PMID: WOS:000395575800006. PMID: 27132010
21. Matheson BE, Douglas JM. Overweight and Obesity in Children with Autism Spectrum Disorder (ASD): a Critical Review Investigating the Etiology, Development, and Maintenance of this Relationship. Review Journal of Autism and Developmental Disorders. 2017; 4(2):142–56. https://doi.org/10.1007/s40489-017-0103-7 PubMed PMID: WOS:000405827000004.

22. Curtin C, E Anderson S, Must A, Bandini L. The prevalence of obesity in children with autism: A secondary data analysis using nationally representative data from the National Survey of Children's Health2010. 11 p.
23. Rastam M. Eating disturbances in autism spectrum disorders with focus on adolescent and adult years. Clinical Neuropsychiatry. 2008; 5(1):31–42.
24. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. Autism. 2016; 20(4):442–62. https://doi.org/10.1177/1362361315588200 PMID: 26134030.
25. Kuschner ES, Eisenberg IW, Otonzi B, Simmons WK, Kenworthy L, Martin A, et al. A Preliminary Study of Self-Reported Food Selectivity in Adolescents and Young Adults with Autism Spectrum Disorder. Research in autism spectrum disorders. 2015; 15–16:53–9. https://doi.org/10.1016/j.rasd.2015.04.005 PubMed PMID: PMC4545503. PMID: 26309446
26. Fodstad JC, Matson JL. A Comparison of Feeding and Mealtime Problems in Adults with Intellectual Disabilities with and Without Autism. Journal of Developmental and Physical Disabilities. 2008; 20 (6):541–50. https://doi.org/10.1007/s10882-008-9116-6
27. Tavassoli T, Baron-Cohen S. Taste Identification in Adults with Autism Spectrum Conditions. Journal of Autism and Developmental Disorders. 2012; 42(7):1419–24. https://doi.org/10.1007/s10803-011-1377-8 PMID: 22006402
28. Tavassoli T, Miller LJ, Schoen SA, Nielsen DM, Baron-Cohen S. Sensory over-responsivity in adults with autism spectrum conditions. Autism. 2014; 18(4):428–32. https://doi.org/10.1177/1362361313477246 PubMed PMID: WOS:000334377400009. PMID: 24085741
29. Crane L, Goddard L, Pring L. Sensory processing in adults with autism spectrum disorders. Autism. 2009; 13(3):215–28. https://doi.org/10.1177/1362361309103794 PMID: 19369385
30. Kollndorfer K, Ohrenberger I, Schöpf V. Contraceptive Use Affects Overall Olfactory Performance: Investigation of Estradiol Dosage and Duration of Intake. PloS one. 2016; 11(12):e0167520–e. https://doi.org/10.1371/journal.pone.0167520 PMID: 28002464.
31. Karlsson L, Rastam M, Wentz E. The SWedish Eating Assessment for Autism spectrum disorders (SWEAA)-Validation of a self-report questionnaire targeting eating disturbances within the autism spectrum. Research in Developmental Disabilities. 2013; 34(7):2224–33. https://doi.org/10.1016/j.ridd.2013.03.035 PubMed PMID: WOS:000319794600018. PMID: 23643773
32. Wallace GL, Kenworthy L, Pugliese CE, Popal HS, White EI, Brodsky E, et al. Real-World Executive Functions in Adults with Autism Spectrum Disorder: Profiles of Impairment and Associations with Adaptive Functioning and Co-morbid Anxiety and Depression. Journal of autism and developmental disorders. 2016; 46(3):1071–83. https://doi.org/10.1007/s10803-015-2655-7 PMID: 26572659.
33. Croen LA, Zerbo O, Qian YG, Massolo ML, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. Autism. 2015; 19(7):814–23. https://doi.org/10.1177/1362361315577517 PubMed PMID: WOS:000361769700006. PMID: 25911091
34. Westwood H, Tchanturia K. Autism Spectrum Disorder in Anorexia Nervosa: An Updated Literature Review. Current Psychiatry Reports. 2017; 19(7). https://doi.org/10.1007/s11920-017-0791-9 PubMed PMID: WOS:000404382500006. PMID: 28540683
35. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007; 19 (6):349–57. https://doi.org/10.1093/intqhc/mzm042 PMID: 17872937
36. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006; 3 (2):77–101.
37. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. Clinical Psychology Review. 2014; 34(1):73–86. https://doi.org/10.1016/j.cpr.2013.11.002 PubMed PMID: WOS:000330752100006. PMID: 24423451
38. Mechling LC, Gustafson M. Comparison of the Effects of Static Picture and Video Prompting on Completion of Cooking Related Tasks by Students with Moderate Intellectual Disabilities. Exceptionality. 2009; 17(2):103–16. https://doi.org/10.1080/09362830902805869 PubMed PMID: WOS:000270938800005.
39. Mechling LC, Ayres KM, Foster AL, Bryant KJ. Comparing the Effects of Commercially Available and Custom-Made Video Prompting for Teaching Cooking Skills to High School Students With Autism. Remedial and Special Education. 2013; 34(6):371–83. https://doi.org/10.1177/0741932513494856 PubMed PMID: WOS:000326240500005.
40. Garfinkel SN, Tiley C, O'Keeffe S, Harrison NA, Seth AK, Critchley HD. Discrepancies between dimensions of interoception in autism: Implications for emotion and anxiety. Biological Psychology. 2016;

114:117–26. https://doi.org/10.1016/j.biopsycho.2015.12.003 PubMed PMID: WOS:000368937900012. PMID: 26724504

41. Tchanturia K, Adamson J, Leppanen J, Westwood H. Characteristics of autism spectrum disorder in anorexia nervosa: A naturalistic study in an inpatient treatment programme. Autism. 2017:1362361317722431. Epub 2017/11/07. https://doi.org/10.1177/1362361317722431 PMID: 29105513.

42. Kinnaird E, Norton C, Stewart C, Tchanturia K. Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment? International Review of Psychiatry. 2019:1–10. https://doi.org/10.1080/09540261.2018.1531831 PMID: 30821179

43. World Health Organisation. Obesity and Overweight Fact Sheet: http://www.who.int/news-room/fact-sheets/detail/obesity-and-overweight; 2018 [cited 2018].

44. Karjalainen L, Gillberg C, Rastam M, Wentz E. Eating disorders and eating pathology in young adult and adult patients with ESSENCE. Comprehensive Psychiatry. 2016; 66:79–86. https://doi.org/10.1016/j.comppsych.2015.12.009 PubMed PMID: WOS:000372760000012. PMID: 26995240

45. Granich J, Lin A, Hunt A, Wray J, Dass A, Whitehouse AJO. Obesity and associated factors in youth with an autism spectrum disorder. Autism. 2016; 20(8):916–26. https://doi.org/10.1177/1362361315616345 PMID: 26893400

46. Healy S, Pacanowski C, Williams E. Weight management interventions for youth with autism spectrum disorder: a systematic review. International Journal of Obesity. 2018.

47. Loomes R, Hull L, Mandy W. What is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. Journal of the American Academy of Child & Adolescent Psychiatry. 2017; 56(5):466–474.

48. Call NA, Simmons CA, Mevers JEL, Alvarez JP. Clinical Outcomes of Behavioral Treatments for Pica in Children with Developmental Disabilities. Journal of Autism and Developmental Disorders. 2015; 45(7):2105–14. https://doi.org/10.1007/s10803-015-2375-z PubMed PMID: WOS:000356351800016. PMID: 25636679

49. Pan CY. Objectively measured physical activity between children with autism spectrum disorders and children without disabilities during inclusive recess settings in Taiwan. Journal of Autism and Developmental Disorders. 2008; 38(7):1292–301. https://doi.org/10.1007/s10803-007-0518-6 PubMed PMID: WOS:000257935100009. PMID: 18157623

Chapter 9: Investigating alexithymia in autism: A systematic review and meta-analysis

Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry, (55)*, 80–89. doi:10.1016/j.eurpsy.2018.09.004

Due to the low quality of the figures in the published paper as reproduced in this chapter, higher quality versions of the figures are included in Appendix F.

European Psychiatry 55 (2019) 80–89

Contents lists available at ScienceDirect

European Psychiatry

journal homepage: http://www.europsy-journal.com

Review/Meta-analyses

Investigating alexithymia in autism: A systematic review and meta-analysis

Emma Kinnaird[a], Catherine Stewart[a,b], Kate Tchanturia[a,b,c,*]

[a] King's College London, London, Institute of Psychiatry, Psychology and Neuroscience, Department of Psychological Medicine, UK
[b] South London and Maudsley NHS Foundation Trust, London, UK
[c] Ilia State University, Tbilisi, Georgia

ARTICLE INFO

Article history:
Received 26 June 2018
Received in revised form 6 August 2018
Accepted 18 September 2018
Available online xxx

Keywords:
Autism
Psychometry and assessments in psychiatry (tests)

ABSTRACT

Background: New research suggests that, rather than representing a core feature of autism spectrum disorder (ASD), emotional processing difficulties reflect co-occurring alexithymia. Autistic individuals with alexithymia could therefore represent a specific subgroup of autism who may benefit from tailored interventions. The aim of this systematic review and meta-analysis was to explore the nature and prevalence of alexithymia in autism using the Toronto Alexithymia Scale (TAS).

Methods: Online scientific databases were searched systematically for studies on ASD populations using the TAS. Meta-analyses were performed to evaluate differences in scores between the ASD and neurotypical groups, and to determine the prevalence of alexithymia in these populations.

Results: 15 articles comparing autistic and neurotypical (NT) groups were identified. Autistic people scored significantly higher on all scores compared to the NT group. There was also a higher prevalence of alexithymia in the ASD group (49.93% compared to 4.89%), with a significantly increased risk of alexithymia in autistic participants.

Conclusions: This review highlights that alexithymia is common, rather than universal, in ASD, supporting a growing body of evidence that co-occurring autism and alexithymia represents a specific subgroup in the ASD population that may have specific clinical needs. More research is needed to understand the nature and implications of co-occurring ASD and alexithymia.

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by difficulties in social communication and interaction, and restricted or repetitive patterns of behaviour or interests [1]. However, ASD has also been associated with difficulties in emotion processing, in particular problems with recognising emotions in others [2,3].

Nonetheless, findings on emotion processing in ASD have been inconsistent [4,5], leading to suggestions these difficulties may not represent a core feature. Rather, it has been suggested that these the problems with emotion processing often observed in ASD instead stem from co-occurring alexithymia [6–8]. First described in the 1970s, alexithymia refers to difficulties in recognising and distinguishing between different emotions and bodily sensations, difficulties in expressing emotions, a lack of imagination or fantasy life, and thoughts focused on external rather than internal experience [9].

Significantly, alexithymia is thought to be heightened in autistic people compared to the general population [10–12]. An increasing body of empirical research supports the hypothesis that emotion processing difficulties in ASD are in fact driven by alexithymia. Studies controlling for both alexithymia and autism have found that alexithymia, rather than autism, predict difficulties in facial, vocal and musical emotion recognition [8,13,14]. Furthermore, imaging research suggests that empathetic brain activity in response to the pain of others is predicted by alexithymia, not autism [15].

There are a number of potential mechanisms which could underpin this relationship between ASD and alexithymia. A meta-analysis of neuroimaging studies suggests that alexithymia may be associated with reduced activation in a number of brain areas associated with emotion processing, specifically the amygdala, mirror neuron system related brain regions, the dorsomedial prefrontal cortex, and the right insula and precuneus [16]. Although more research is needed on the potential links to alexithymia in this population, autism is known to be associated

* Corresponding author at: King's College London, London, Institute of Psychiatry, Psychology and Neuroscience, Department of Psychological Medicine, UK.
E-mail address: kate.tchanturia@kcl.ac.uk (K. Tchanturia).

http://dx.doi.org/10.1016/j.eurpsy.2018.09.004
0924-9338/

with atypical neural connectivity, including in the amygdala and insula [17–19]. Consequently, it has been proposed that both autism and alexythmia may both be associated with a genetic vulnerability to atypical brain connectivity that can manifest as either "pure" autism, "pure" alexithymia, or co-occurring autism and alexithymia, depending on the exact networks affected [6].

Alternatively, another potential shared mechanism between alexithymia and autism could be that of mentalizing: both constructs are known to be associated with mentalizing difficulties [20,21]. However, an imaging study found that difficulties in emotional awareness in autistic people was not associated with variations of brain activity in the mentalizing system [3]. Rather, these difficulties were associated with reduced activation in the anterior insula, an area thought to be key in enabling the conscious representation of feelings, and highly correlated in this study with self-rated alexithymia. Consequently, the authors concluded that their findings supported "decoupling" models of alexithymia, where the physiological arousal induced by an emotional state is not integrated with conscious awareness of this arousal. Significantly, this could represent a key shared mechanism between autism and alexithymia, reflecting research suggesting that there is a disruption between how autistic individuals subjectively experience their emotions, and their physiological emotional arousal [20]. Consistent with this hypothesis are findings from a recent study finding that self-reported alexithymia was associated with reduced skin conductance, suggesting reduced emotional experience, and disruption between subjectively and objectively reported measures of emotional arousal, supporting the role of decoupling in alexithymia and autism [22].

However, not all autistic people have alexithymia, with a recent study finding a prevalence rate of 55% in autistic adolescents [23]. Consequently, Bird & Cook [6] have proposed the "alexithymia hypothesis" of ASD: that the emotion processing difficulties seen in ASD stem from co-occurring alexithymia, rather than representing a core feature. In line with this hypothesis, research has found that alexithymia, and not ASD, is predictive of problems with emotion processing [8].

This suggests that individuals with both alexithymia and ASD represent a distinct subgroup of autistic people who may benefit from interventions that could help manage these emotional

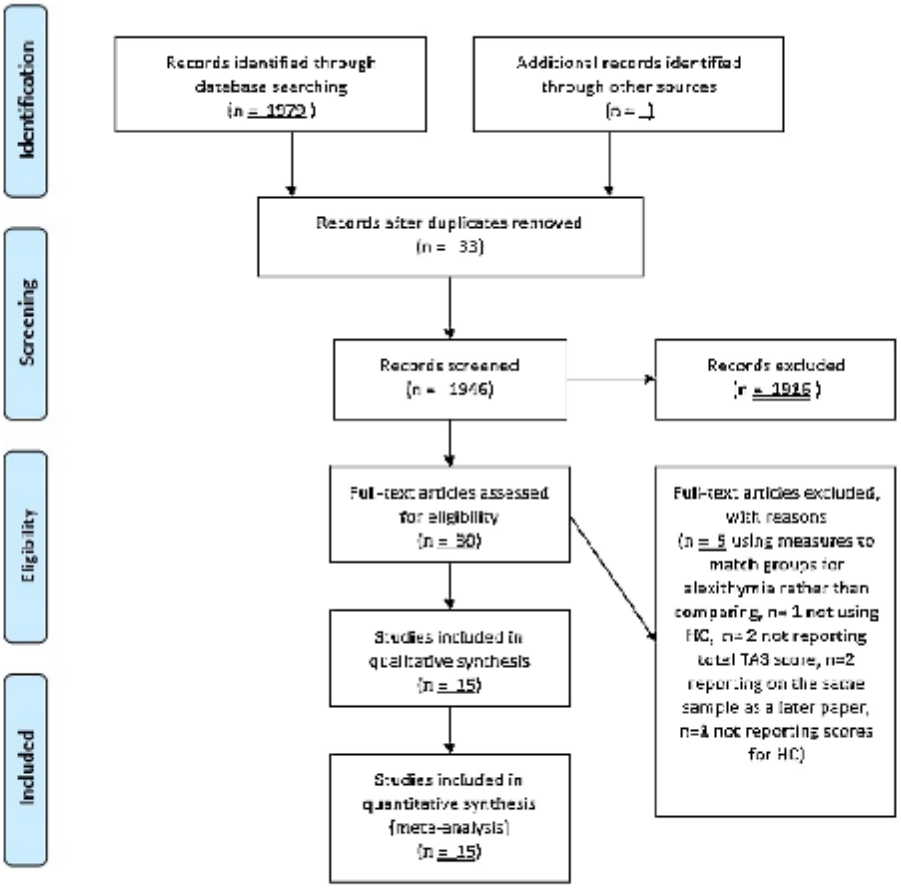


Fig. 1. PRISMA diagram of selection process.

processing difficulties [24]. Understanding the potential co-occurrence of alexithymia in autism is vital for both clinical and research purposes. Alexithymia may be associated with additional difficulties for autistic people, with this same adolescent study finding that individuals with both ASD and alexithymia experienced higher levels of anxiety and emotional difficulties compared to those with ASD only [23]. Moreover, autistic people are known to be at heightened risk for a number of mental health problems [25], and alexithymia is associated with poorer outcomes for psychotherapeutic treatment [26]. Therefore, individuals with co-occurring autism and alexithymia may benefit from targeted interventions, such as training in identifying and communicating feelings, or mindfulness exercises ([27] [28];). The alexithymia hypothesis also has significant implications for future research on emotion processing in ASD, suggesting that it may be necessary for future studies on this and related areas to control for alexithymia in their design and analysis [8].

At present, the measurement of alexithymia primarily relies on self-report measures requiring participants to reflect on their difficulties with identifying their emotions, which, when measuring a construct associated with problems reflecting on emotion identification, has been noted as a counter-intuitive approach (Gaigg, Cornell & Bird., 2016). However, the above study examining the variance between self-reported subjective emotional arousal, and objective arousal as measured by skin conductance, in autistic and control participants, found good correlations between self-report alexithymia measures and this objective, experimental method (Gaigg, Cornell & Bird., 2016). In 2005, Berthoz & Hill confirmed that the 20-item Toronto Alexithymia Scale (TAS-20) can be used to reliably identify alexithymia in an ASD population, with the measure demonstrating good convergent validity [10]. There is also a longer, 26 item version of this measure known as the TAS-26. The TAS-20 presents participants with 20 items, to which they rate their level of agreement on a Likert Scale from 1 (strongly disagree) to 5 (strongly agree) [29]. This yields an overall total score, with a score of 61 and above indicating high levels of alexithymia. The TAS-20 additionally generates scores for three subscales measuring difficulty identifying feelings (DIF); difficulty describing feelings (DDF) and externally-oriented thinking (EOT). Therefore, the TAS may be used to assess the presence of alexithymia in autistic people. However, the TAS does have some key weaknesses: it does not measure the fantasy aspect of alexithymia, and the EOT scale may lack reliability [30]. Consequently, it has been recommended that the TAS should not be the only measure used to evaluate alexithymia. Commonly used alternative measures include the Bermond-Vorst Alexithymia Questionnaire (BVAQ), which does include the fantasy construct [31].

As well as giving insight into the prevalence of alexithymia in ASD, a systematic review is necessary to illuminate the use of the TAS in ASD, including consideration of confounding variables and the utilisation of additional measures. Therefore, this review aimed to synthesise the literature on the use of the TAS in autistic people by using a meta-analysis to explore differences between ASD and NT groups on alexithymia scores. It is predicted that autistic people will experience heightened levels of alexithymia compared to NT groups, but that not all autistic people will experience alexithymia.

2. Methods

The study was conducted according to PRISMA guidelines [32].

2.1. Eligibility

This review included studies using either the TAS-20 or TAS-26 with both ASD and neurotypical (NT) populations. Inclusion criteria were 1) full text available in English, 3) published in a peer reviewed journal, 3) reporting a comparison of total mean TAS scores for both populations with standard deviations. Studies which used the TAS to match ASD and NT groups for alexithymia, rather than comparison, were also excluded.

2.2. Information sources and search

The databases PsychInfo, Scopus, Pubmed and Web of Science were searched for papers up to and including January 2018. The search terms were autis* and alexithymia, and Toronto Alexithymia Scale. "Or" Bermond-Vorst Alexithymia Questionnaire (BVAQ) was additionally incorporated as a search term in order to highlight papers utilising this common additional measure for alexithymia in this population.

2.3. Selection

The selection process is summarised in Fig. 1. Following the exclusion of duplications, the titles of papers were screened for relevance. Abstracts of titles which appeared to potentially meet the criteria were then screened. Full texts were retrieved if the abstract indicated that inclusion criteria were met, or if there was not sufficient information in the abstract to warrant a decision. Full texts were reviewed, with any that did not meet the inclusion criteria excluded with reasons given.

2.4. Data collection and items

The following data was extracted from each paper: gender and age of participants, how ASD and NT groups were matched, TAS version, use of additional alexithymia measures, recruitment source, how ASD was diagnosed, comorbidities assessed, mean total TAS scores with subscale scores if reported, and number of participants in each group scoring above cut-off for alexithymia on the TAS-20 (defined as >61).

2.5. Risk of bias across studies

Risk of bias across studies was assessed visually using funnel plots, plotting standard error against standard mean difference (effect size). The Duval and Tweedie nonparametric "trim and fill" method was also implemented using the *metatrim* command in Stata15 to assess publication bias by estimating the number and outcomes of missing studies. Between-study heterogeneity was measured using the Cochrane Q test.

2.6. Risk of bias in individual studies

Risk of bias for each study was assessed by evaluating the quality of each study using the Clinical Appraisal Skills Programme Checklist for case-control studies, in line with previous research in this area [33]. The tool uses 11 questions to assess study quality, including whether potential confounding variables were accounted for in analysis or study design, and how participants were recruited. An overall quality rating was calculated by dividing several questions into sub-questions with a score of 1 for every "yes" response, giving a maximum quality rating of 17.

2.7. Summary measure

The principle measure used for meta-analysis was the difference between ASD and NT groups on mean scores and standard deviations on the TAS total score, and, if reported, subscale scores. Where studies had subdivided their ASD and NT groups into smaller sub-groups, such as by gender, these scores

Table 1
Summary of studies included in systematic review.

Year	Author	Group	N	Gender (male (female))	Mean Age (SD)	NTs Matched By	TAS Version	Additional measure?	Recruitment Source	ASD Diagnostic Tool	Comorbidities assessed	TAS Total Score	N (%) Above cut-off (>61)	TASF1 DIF	TASF2 DDF	TASF3 EOT	Quality Score
2017	Arellano et al.	ASD	14	14 (0)	15.33 (0.99)	Age, IQ	TAS-26	BVAQ-AB				48.79 (9.78)		14.07 (6.03)	14.14 (5.20)	15.57 (3.20)	9
		NT	21	14 (0)	15.64 (1.15)							37.15 (7.32)		10.50 (3.10)	11.40 (4.01)	15.25 (3.99)	
2017	Murray et al.**	ASD	19	20 (0)	30.60 (6.52)	Age, gender, verbal ability	TAS-20		ASD diagnostic service	ICD-10		61.58 (10.07)	11 (52.6%)	20.58 (5.98)	17.95 (3.46)	23.05 (4.48)	13
		NT	20	19 (1)	30.65 (6.27)							46.60 (11.10)	4 (20%)	15.60 (6.02)	12.95 (5.27)	18.05 (4.44)	
2017	Schaller & Rauh.	ASD	23	23 (0)	15.72 (1.25)	Gender, age, nonverbal intelligence	TAS-26		University project databases	ADOS, ADI-R		45.32 (7.63)		14.64 (5.01)	14.96 (3.51)	15.65 (3.26)	13
		NT	22	22 (0)	15.85 (0.97)							38.36 (6.73)		10.82 (3.43)	11.6 (3.50)	15.86 (3.37)	
2016	Hoffmann et al.	ASD	25	25 (0)	32.6 (8.5)	IQ, gender	TAS-26		Outpatient clinic, referral from clinician	ADOS, ADI-R		54.2 (10.0)					13
		NT	25	25 (0)	32.4 (8.5)							37.4 (7.8)					
2016	Milosavljevic et al.*	ASD	56	54 (2)	15.45 (0.48)	Age, gender	TAS-20		Prior autism prevalence study cohort	ADOS, ADI-R	Depression, anxiety	53.11 (11.64)	31 (55%)	16.34 (6.28)	13.63 (4.34)	23.14 (4.23)	14
		NT	32	32 (0)	15.5 (0.57)							45.63 (11.64)	5 (16%)	12.03 (5.45)	10.97 (4.53)	22.63 (3.51)	
2016	Patil et al.	ASD	15		37.35 (13.02)	Age, gender, education	TAS-20		ASD organisations, internet communities	ICD-10	Depression	53.60 (8.63)	7 (47%)	20.13 (5.01)	20.20 (2.51)	13.27 (3.37)	12
		NT	16		32.03 (9.44)							34.75 (3.96)	0 (0%)	9.63 (1.86)	11.38 (2.19)	13.75 (2.52)	
2015	Kuch et al.	ASD	16	16 (0)	21.5	Age, gender, verbal IQ	TAS-20			ICD-10, ADOS, ADI-R		55.53 (14.3)					11
		NT	16	16 (0)	24.3							44.93 (10.02)					
2013	Berthoz et al.	ASD	38	63% male	35.5 (13.3)	Age & gender accounted for in analysis	TAS-20	BVAQ-B	Support groups and community centres	DSM-IV	Depression, anxiety	61.4 (12.2)	21 (55.3%)	21.6 (6.7)	18.1 (4.2)	21.7 (5.1)	15
		NT	47	62% male	33.7 (11.7)							40.0 (9.2)	1 (2.1%)	13.7 (6.4)	11.5 (5.2)	17.7 (4.8)	
2013	Schneider et al.*	ASD	28	15 (13)	31.39 (8.97)	Gender, age, education	TAS-20		Inpatient and outpatient facilities			59.88 (11.61)					13
		NT	27	15 (12)	31.42 (9.08)							39.48 (9.96)					
2012	Heaton et al.	ASD	20	15 (5)	33.70 (12.77)	Age, IQ, gender	TAS-20		National Autistic Society website, social groups, community centres	DSM		60.70 (15.47)	9 (45%)				13
		NT	20	15 (5)	33.60 (12.06)							36.10 (8.85)	0 (0%)				
2012	Samson et al.	ASD	27	11 (16)	33.56 (12.82)	Gender, age, educational level completed	TAS-20		Participants in previous studies			61.41 (10.85)	17 (63%)	23.63 (4.76)	18.19 (4.24)	19.59 (4.67)	13
		NT	27	11 (16)	35.22 (12.82)							42.70 (10.35)	0 (0%)	14.52 (5.15)	11.22 (3.66)	16.96 (3.95)	
2008	Katsyri et al.	ASD	20	13 (7)	32 (10)	Age, gender	TAS-20		Neurology hospital, ASD clinic	ICD-10, DSM-IV, ADOS, ADI-R		55 (12)	7 (35%)	21 (5)	16 (6)	18 (5)	13
		NT	20	13 (7)	31 (8)							36 (6)	0 (0%)	11 (3)	9 (2)	15 (5)	
2008	Silani et al.	ASD	15	13 (2)	36.6 (11.7)	Age, IQ, gender	TAS-20	BVAQ-B		DSM-IV, ADOS		55.6 (9.7)	5 (33.3%)	18.5 (6.5)	17.2 (4.2)	19.9 (3.1)	12
		NT	15	13 (2)	33.7 (10.3)							43.7 (12.7)	1 (0.1%)	14.3 (5.3)	11.8 (4.4)	17.6 (5.3)	

Table 1 (Continued)

Year	Author	Group	N	Gender (male (female))	Mean Age (SD)	NTs Matched By	TAS Version	Additional measure?	Recruitment Source	ASD Diagnostic Tool	Comorbidities assessed	TAS Total Score	N (%) Above cut-off (>61)	TASF1 DIF	TASF2 DDF	TASF3 EOT	Quality Score
2007	Lombardo et al.	ASD	30	23 (7)	29.13 (7.40)	Age, gender	TAS-20			DSM-IV, ICD-10		58.37 (14.89)		20.03 (6.70)	16.87 (5.62)	21.47 (4.90)	11
		NT	30	23 (7)	29.93 (7.83)							41.97 (9.19)		13.50 (4.82)	11.10 (4.85)	17.37 (4.36)	
2004	Tani et al.	ASD	20	14 (6)	27.2 (7.3)	Age, gender, intelligence, body mass index (BMI)	TAS-20		Autism clinic	DSM-IV, Autism Spectrum Screening Questionnaire, SCID	Depression	54.2 (12.4)	8 (40%) 0 (0%)	19.7 (5.8)	15.6 (5.1)	18.9 (5.3)	14
		NT	10	7 (3)	26.5 (8.1)							34.5 (5.1)		10.3 (3.3)	8.7 (1.9)	15.5 (3.8)	

TASF1: difficulties in identifying feelings,TASF2: difficulty in describing feelings,TASF3: externally oriented thinking.
- Data from separate groups collected into ASD and NT using Stata 15.
– Percentage above cut-off converted into number of participants.

were combined into overall ASD and NT means using the *combine* command in Stata 15. For the prevalence and risk ratio analysis, the principle measure was the number of autistic people scoring as alexithymic on the TAS compared to NT. Due to the requirements of the analysis, where studies only reported percentages of participants scoring as alexithymic in each group this was converted using sample size information into the number of participants and, if necessary, rounded to the nearest whole number.

2.8. Synthesis of data

The meta-analysis brought together all studies reporting mean TAS scores, and standard deviations for ASD and NT groups. Standardised mean differences were used to compare studies as some studies used the TAS-26, whilst other used the shorter TAS-20. The meta-analysis used a random effects model. This model accounts for between study heterogeneity and adjusts the study weights accordingly.

2.9. Statistical analyses

Meta-analyses were conducted using Review Manager 5.3, with some additional functions performed using Stata15 [34]. Comparison of TAS total and subscale scores between groups was calculated by using Cohen's *d* to estimate effect sizes for each study, interpreted as small (0.2), medium (0.5) or large (0.8). A positive effect size indicated that the ASD group scored higher on the TAS mean scores compared to the NT group. Following initial analyses, meta-regression was performed in Stata15 using the *metreg* command to analyse associations between overall TAS score, mean age, and age difference between ASD and NT groups. A weighted prevalence rate was calculated by weighting the mean percentage of participants scoring above the cut-off for each group according to the number of participants in each study. The Cochrane-Mantel-Haenszel random effects estimate method was used to calculate the risk ratio of scoring above the TAS cut-off for alexithymia in ASD compared to NT groups.

3. Results

3.1. Study selection

The systematic review identified 17 studies as eligible for inclusion. Three studies reported on an overlapping sample, with data from some participants being used in multiple studies [10,12,35]. For the purposes of this analysis, the most recent paper only [35] was used as it represented the largest sample. Therefore, a total of 15 studies were included in this systematic review.

3.2. Study characteristics

The 15 studies evaluated in this systematic review are summarised in Table 1. 12 studies used the TAS-20, whilst 3 studies used the longer TAS-26. 11 studies reported subscale scores, and 9 studies reported how many individuals in each group scored above the cut-off for alexithymia.

Quality of individual studies was generally high: all studies reported mean age, and all studies aside from Patil et al (2016) reported participant gender. Additionally, all studies matched ASD and NT groups on at least some characteristics, most commonly gender and age. The lowest scoring study on the quality appraisal was Arellano et al. [36], due to a lack of information on how participants were recruited, and how ASD diagnoses were defined or confirmed. The highest scoring study on the quality appraisal was Berthoz et al. [35], primarily due to their consideration of confounding factors in the analysis. Only a minority of studies

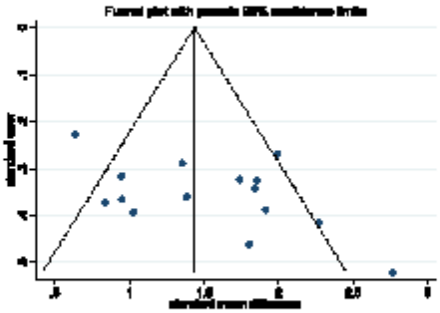


Fig. 2. Funnel plot of studies included in the meta-analysis for the assessment of publication bias.

assessed the potential confounding factors of anxiety or depression, and only one study accounted for these factors in their analysis. Berthoz et al. [35] presented group comparisons between ASD and NT for both levels of alexithymia unadjusted for confounding factors, and alexithymia adjusted for depression, as measured by the Beck Depression Inventory [37], and anxiety measured using the State Trait Anxiety Inventory Form Y [38]. Differences between the ASD and NT group on both the TAS total score and all subscale scores remained significant following the control for anxiety and depression.

Despite previous recommendations that the TAS should not be used in isolation, only three studies used an additional measure to assess the presence of alexithymia [30]. In all cases, this was a version of the Bermond-Vorst Alexithymia Questionnaire. Two studies found a correlation between the BVAQ and TAS total scores [35,36], whilst the third study did not report this information [3]. Further information on study quality appraisals may be found in the appendix.

3.3. Meta-analysis

3.3.1. Risk of Bias

The funnel plot for total TAS scores is shown in Fig. 1. The funnel plot suggested a potential publication bias due to its asymmetrical appearance, with a small gap in the lower left hand corner of the graph suggesting that smaller effect size studies may be missing from this review of published papers. However, further analysis using the trim and fill method indicated that no studies were missing, with estimated effect sizes remaining unchanged.

3.3.2. TAS score comparison

The forest plots of studies comparing groups on total and subscale TAS scores are displayed in Figs. 2–6. Data were extracted from 15 studies giving an overall sample size of 366 autistic people, and 348 NT individuals. The random effects analysis revealed a significant difference between the groups with a large effect size ($d = 1.51$, (95% CI 1.21, 1.81), $Z = 9.90$, $p < 0.001$).

11 studies additionally presented mean scores for ASD and NT groups on the TAS subscales: difficulty identifying feelings (DIF); difficulty describing feelings (DDF) and externally-oriented thinking (EOT). This produced an overall sample size of 292 autistic people, and 275 NT individuals. The random effects analysis revealed a significant difference with a large effect size between the groups for the DIF subscale ($d = 1.28$, (95% CI 0.96, 1.60), $Z = 7.81$, $p < 0.001$) and DDF subscale ($d = 1.29$, (95% CI 0.94, 1.64), $Z = 7.21$, $p < 0.001$). There was also a significant difference between groups on the EOT subscale, with a medium effect size ($d = 0.50$, (95% CI 0.25, 0.75), $Z = 3.91$, $p < 0.001$).

Results suggested significant heterogenity in the overall TAS score meta-analysis ($X^2 = 41.39$, $p < 0.001$). Consequently, a meta-regression was performed to analyse associations between overall TAS score, mean age, and age difference between clinical and control groups. There was a significant effect of mean age on outcome, (b = 0.05 (95% CI 0.03, 0.08), t = 4.51, $p < 0.001$), but no

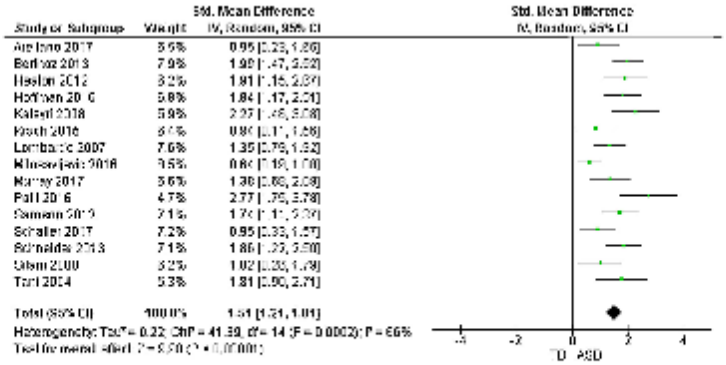


Fig. 3. Forest plot of standardized mean effect size for differences between ASD and NT groups on total TAS scores.

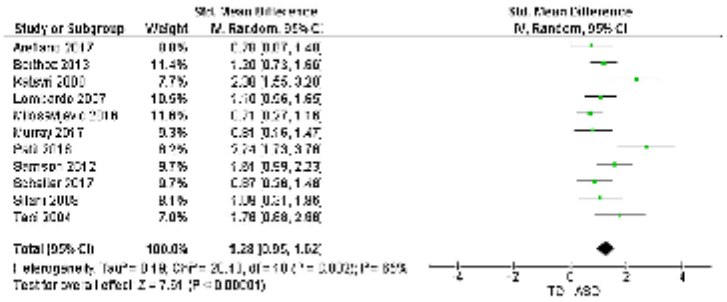


Fig. 4. Forest plot of standardized mean effect size for differences between ASD and NT groups on DIF scores.

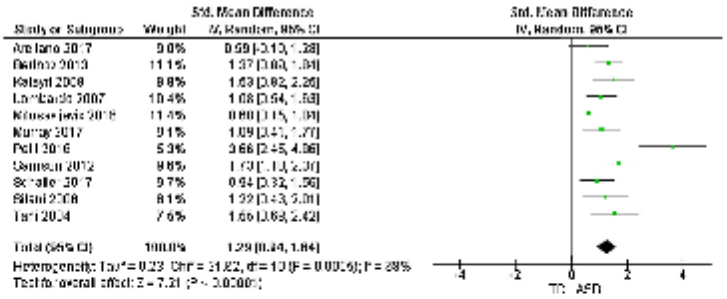


Fig. 5. Forest plot of standardized mean effect size for differences between ASD and NT groups on DDF scores.

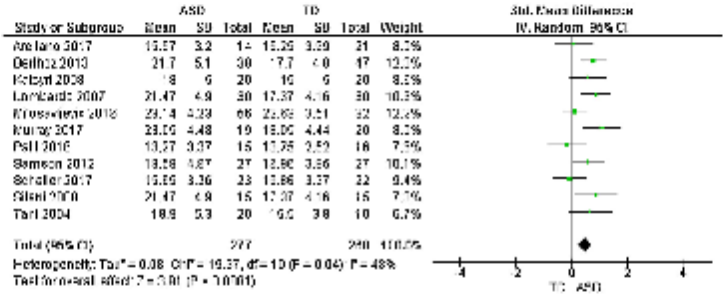


Fig. 6. Forest plot of standardized mean effect size for differences between ASD and NT groups on EDT scores.

significant effect for age difference between groups (b = 0.04 (95% CI -0.11, 0.18), t = 0.56, p = 0.586).

3.3.3. *Alexithymia prevalence and risk ratio*

9 studies used previously established cut-off scores to categorise participants as alexithymic or non-alexithymic, with a TAS-20 score of 61–100 indicating alexithymia [29]. In these papers, prevalence rates of alexithymia in the ASD groups ranged from 33.3% to 63%, with a mean weighted prevalence rate of 49.93%. Prevalence rates in the NT groups ranged from 0% to 20%, with a mean weighted prevalence rate of 4.89%.

The Cochran-Mantel-Haenszel random effects analysis revealed an overall risk ratio of 6.50 (95% CI 3.26–12.93, $p < 0.001$) for scoring above the cut-off for alexithymia in autistic people compared to NT (Fig. 7), suggesting a significantly increased risk of alexithymia in the ASD group.

4. Discussion

Research suggests that, far from being a core feature of ASD, emotional processing difficulties instead represent a sub-group with co-occurring alexithymia who may have unique needs, particularly surrounding mental health vulnerability and treatment. However, current estimates of the prevalence of alexithymia in ASD vary, with this paper finding estimates between 33.3% and 63%. This was the first systematic review and meta-analysis aimed

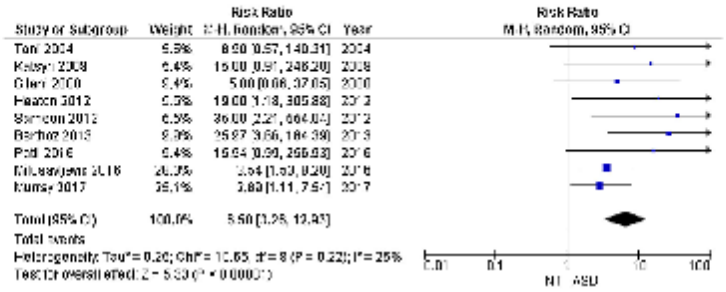


Fig. 2. Forest plot of relative risk of scoring above TAS cut-off for ASD and NT groups with confidence intervals.

at exploring alexithymia in ASD using the self –report TAS, a commonly used measure in this field. 15 studies were examined, representing a total of 366 autistic people, and 348 NT individuals. The findings of the meta-analysis suggest that significant differences exist between ASD and NT groups on both total and subscale scores of the TAS, with ASD groups scoring higher on the TAS with medium to large effect sizes. This confirms that autistic people are more likely to experience higher levels of alexithymia compared to their NT counterparts. Furthermore, there was a higher prevalence of alexithymia in the ASD (49.93%) compared to the NT group (4.89%), indicating that alexithymia is common, although not universal, in autistic people. This supports the hypothesis suggesting that an alexithymic subgroup does indeed exist in ASD, and that up to 50% of autistic individuals may be vulnerable to the emotional processing difficulties, and heightened mental health problems, associated with elevated alexithymia [24].

Consistent with previous research in this area, the TAS was found to discriminate between autistic people and NT, with autistic people scoring higher on both total and subscale scores compared to NT. This included on the EOT subscale: research into the use of the TAS in different clinical populations, such as eating disorders, has suggested that the EOT may not discriminate between cases and controls as successfully as the other subscales [33], and the reliability of the subscale across different populations has been questioned [30,39,40]. However, in the present study autistic people were found to score higher on the EOT subscale, albeit with only a medium effect size compared to the large effect sizes exhibited by the total, DIF and DDF subscale scores. This provides further support for the suitability of the TAS, including the subscale scores, in ASD research.

Nonetheless, this review highlighted a number of methodological issues in the application of the TAS in this field. Firstly, the TAS has been criticised previously for not capturing the whole of the alexithymia construct, including the absence of items measuring fantazing or emotionalizing [41]. Consequently, it has been suggested that the TAS should be used together with other measures when exploring alexithymia in ASD, such as the BVAQ [31]. Moreover, an informant based measure such as the Observer Alexithymia Scale may be particularly useful in analysing the presence of alexithymia as the very nature of alexithymia, limiting an individual's ability to reflect on their own emotions, may additionally inhibit their ability to complete self-report instruments on the subject [42]. However, in this study only three studies used an additional measure- the BVAQ- to assess the presence of alexithymia.

Furthermore, the meta-analysis identified high levels of heterogenity across studies. That mean age was found to impact alexithymia scores in this study is consistent with research suggesting that increasing age is strongly associated with higher levels of alexithymia in a non-clinical population [43]. However, there are a number of additional factors that may have accounted for this heterogenity not captured in the methodology used by the studies in this review. In particular, alexithymia is closely related to depression and anxiety, and both of these conditions are known to be common comorbidities in autistic people [44–47]. Despite this, only one study accounted for depression and anxiety levels in its comparison of TAS scores between ASD and NT groups, finding that differences between the groups reduced but remained significant [35]. This suggests that anxiety and depression may indeed be important confounders when analysing alexithymia in ASD, and highlights the need for future research to consider these variables.

Nonetheless, that only one study considered for the role of confounding factors when analysing alexithymia differences between ASD and NT groups may reflect that, in the majority of studies assessed, alexithymia was not the main focus of the research. Rather, the TAS itself was being used to account for alexithymia as a potentially confounding factor in the area under investigation, such as sleep [48] or social cognition [49]. With an increasing interest in whether individuals with both alexithymia and ASD represent a distinct ASD subtype, any future research using the TAS to explore the alexithymia construct in ASD should address the methodological issues raised in this review, including the use of additional measures and accounting for the significance of potential confounders in analysis [8,24].

The findings from the current review contribute towards the wider literature on alexithymia and related difficulties in ASD. That autistic people were found to score higher on the Difficulty Describing Feelings (DDF) and Difficulty Identifying Feelings (DIF) subscales is consistent with research documenting that the difficulties with recognising, identifying and describing emotions characteristic of alexithymia are also known to be present in ASD [50]. Autistic people are more likely than NT to claim not to feel any emotion, exhibit poorer emotion recognition, have a poorer memory for emotionally significant information, spontaneously mention emotion in conversation, and direct fewer attentional resources towards emotional stimuli [51–54]. Nonetheless, reviews of the available evidence strongly suggest that these difficulties are not unequivocal across ASD, with studies indicating that autistic people are generally able to perceive and identify simple emotions [50,55].

That the symptoms of alexithymia may be a sometimes co-occurring, but not core feature of ASD is supported by the findings of this review. Whilst the meta-analysis found that autistic people score higher on the TAS compared to NT, and are at greater risk of scoring as clinically alexithymic, it is important to note that not all autistic people captured in this review were alexityhmic. Of the papers examining cut-off rates, prevalence rates of alexithymia in the ASD groups ranged from 33.3% [3] to 63% [56], with a weighted

mean prevalence rate of 49.93% compared to 4.89% in the NT groups. This highlights that, even at an upper estimate, nearly 40% of autistic people do not experience high levels of alexithymia, suggesting that although alexithymia may be common in autistic people, not everyone on the spectrum will experience alexithymia. This is consistent with the alexithymia hypothesis of ASD, and suggests that the nature and implications of co-occurring ASD and alexithymia warrants future research [8]. In particular, future research should examine the differences between individuals with co-occurring ASD and alexithymia, and ASD only. With research suggesting that increased rates of alexithymia in autism are associated with heightened anxiety and emotional difficulties compared to those with ASD only, it seems likely that the nearly 50% of autistic individuals with this co-occurring individiuals may have unique needs that require specific interventions [23]. On the basis of previous studies identifying alexithymia as a vulnerability factor for mental illness, particularly depressive disorders, future research should examine whether autistic individuals with alexithymia are indeed at a greater risk of developing mental health problems than those with ASD only [57]. Significantly, alexithymia has also been linked to a number of other negative health outcomes, including increased risk taking behaviour, poor physical health, and increased psychosomatic illness [58]. Further research is necessary to examine how co-occurring alexithymia in autism may result in unique needs, and how best these needs can be identified and met. Potential future directions could include screening autistic people for alexithymia to identify those at risk of associated health problems, particularly in mental health treatment settings where co-occurring alexithymia could be associated with poorer outcomes.

4.1. Limitations

One potential limitation of this study was that two different scales were included in the systematic review: the TAS-26, and the TAS-20. However, these are two highly similar measures: the TAS-20 was developed out of its earlier version, the TAS-26. The TAS-20 has a number of benefits compared to the TAS-26, including fewer items, and greater internal consistency, potentially reflecting why the majority of the studies captured in this review used the 20, rather than the 26 version ([29]; Kooiman, Spinhoven, & Trijsburg, 2003). However, the two measures significantly correlate with each other, even when controlling for depression, suggesting these are similar measures [30]. Moreover, steps were taken in the methodology to minimise the impact of using two different scales: standardised mean differences were used to compare mean scores, and only the TAS-20 was included in the prevalence analysis.

The variability of information reported across studies made direct comparison difficult, and particularly limited the ability of the meta-analysis to explore possible contributions towards the heterogenity of the findings: in particular, the meta-analysis was unable to explore potentially relevant factors including gender, depression and anxiety. Furthermore, the TAS was used in this study as a summary measure to explore alexithymia in ASD due to its widespread use in research. However, the limitations of the TAS, including the absence of items measuring fantazing, limited the ability of this review to further explore the nature of the alexithymia construct in this population. Previous research using additional alexithymia measures, such as the BVAQ, have highlighted that autistic people may have more difficulties with the cognitive aspects of alexithymia (for example identifying and verbalising emotions) rather than a lack of awareness of conscious experience [10]. However, the low number of studies using such an additional measure made it impossible to further explore these aspects in this review. Moreover, the TAS has only been validated for use in what has previously been described in the literature as "high-functioning" ASD, and consistently with this a large number of studies identified in this review specified that they recruited individuals with "high-functioning" ASD only [10]. The use of this self-report format may have excluded individuals with language or communication difficulties. Firstly, this means that the findings of this systematic review may not be generalisable across the ASD spectrum, but rather reflect those individuals specifically with no language or communication problems, and normal to high IQs. This is significant as a review of the literature suggested that there may in fact be more evidence for difficulties with emotional language in this specific ASD population, compared to those with additional intellectual disability or language problems [50]. Therefore, the question of whether alexithymia is heightened across the ASD spectrum requires further research using other, more appropriate measures.

5. Conclusions

By examining the use of the TAS in autistic people, this review demonstrated that up to 50% of autistic people experience co-occurring alexithymia: alexithymia appears to be heightened although not universal, in this population. This provides support for the alexithymia subgroup hypothesis of ASD, and for previous research indicating that emotional processing difficulties traditionally associated with ASD are in fact rooted in co-occurring alexithymia, rather than representing a core feature of ASD itself [6]. Further research is needed into the clinical implications, and the potential for targeted treatments, for this group. However, this review also highlighted methodological issues in the use of the TAS in ASD research that should be accounted for in future research. In particular, future studies exploring alexithymia in ASD should consider the use of additional measurements in tandemn with the TAS, and consider the role of the potentially confounding comorbidities of anxiety and depression in analysis.

Declarations of interest

None.

Acknowledgements

Funding: This work was supported by the MRC and MRF Child and Young Adult Mental Health (the underpinning aetiology of self harm and eating disorders), the Swiss Anorexia Nervosa Foundation (grant 58-16), and the MRC Doctoral Training Partnership in Biomedical Sciences (MR/N013700/1).

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi: https://doi.org/10.1016/j.eurpsy.2018.09.004.

References

[1] APA. Diagnostic and statistical manual of mental disorders. 5 ed. Arlington, VA: American Psychiatric Publishing; 2013.
[2] Guastella AJ, Einfeld SL, Gray KM, Rinehart NJ, Tonge BJ, Lambert TJ, et al. Intranasal oxytocin improves emotion recognition for youth with autism Spectrum disorders. Biol Psychiatry 2010;67(7):692–4, doi: http://dx.doi.org/10.1016/j.biopsych.2009.09.020.
[3] Silani G, Bird G, Brindley R, Singer T, Frith C, Frith U. Levels of emotional awareness and autism: an fMRI study. Soc Neurosci 2008;3(2):97–112, doi: http://dx.doi.org/10.1080/17470910701577020.
[4] Harms MB, Martin A, Wallace GL. Facial emotion recognition in autism Spectrum disorders: a review of behavioral and neuroimaging studies. Neuropsychol Rev 2010;20(3):290–322, doi:http://dx.doi.org/10.1007/s11065-010-9138-6.
[5] Uljarevic M, Hamilton A. Recognition of emotions in autism: a formal meta-analysis. J Autism Dev Disord 2013;43(7):1517–26, doi:http://dx.doi.org/10.1007/s10803-012-1695-5.

[6] Bird G, Cook R. Mixed emotions: the contribution of alexithymia to the emotional symptoms of autism. Transl Psychiatry 2013;3:. doi:http://dx.doi.org/10.1038/tp.2013.61.

[7] Brewer R, Happe F, Cook R, Bird G. Commentary on "Autism, oxytocin and interoception": alexithymia, not Autism Spectrum disorders, is the consequence of interoceptive failure. Neurosci Biobehav Rev 2015;56:348–53, doi:http://dx.doi.org/10.1016/j.neubiorev.2015.07.006.

[8] Cook R, Brewer R, Shah P, Bird G. Alexithymia, not autism, predicts poor recognition of emotional facial expressions. Psychol Sci 2013;24(5):723–32, doi:http://dx.doi.org/10.1177/0956797612463582.

[9] Sifneos PE. The prevalence of "Alexithymic" characteristics in psychosomatic patients. Psychother Psychosom 1973;22(2–6):255–62.

[10] Berthoz S, Hill EL. The validity of using self-reports to assess emotion regulation abilities in adults with autism spectrum disorder. Eur Psychiatry 2005;20(3):291–8. https://doi.org/10.1016/j.eurpsy.2004.06.013.

[11] Fitzgerald M, Bellgrove MA. The overlap between Alexithymia and ASPERGER'S Syndrome. J Autism Dev Disord 2006;36(4):573–6, doi http://dx.doi.org/10.1007/s10803-006-0096-z.

[12] Hill E, Berthoz S, Frith U. Brief report: cognitive processing of own emotions in individuals with autistic Spectrum disorder and in their relatives. J Autism Dev Disord 2004;34(2):229–35, doi: http://dx.doi.org/10.1023/b:jadd.0000022613.41399.14.

[13] Allen R, Davis R, Hill E. The effects of autism and Alexithymia on physiological and verbal responsiveness to music. J Autism Dev Disord 2013;43(2):432–44, doi:http://dx.doi.org/10.1007/s10803-012-1587-8.

[14] Heaton P, Reichenbacher L, Sauter D, Allen R, Scott S, Hill E. Measuring the effects of alexithymia on perception of emotional vocalizations in autistic spectrum disorder and typical development. Psychol Med 2012;42(11):2453–9, doi:http://dx.doi.org/10.1017/S0033291712000621.

[15] Bird G, Silani G, Brindley R, White S, Frith U, Singer T. Empathic brain responses in insula are modulated by levels of alexithymia but not autism. Brain 2010;133(5):1515–25, doi:http://dx.doi.org/10.1093/brain/awq060.

[16] van der Velde J, Servaas MN, Goerlich KS, Bruggeman R, Horton P, Costafreda SC, et al. Neural correlates of alexithymia: a meta-analysis of emotion processing studies. Neurosci Biobehav Rev 2013;37(7):1774–85.

[17] Caria A, de Falco S. Anterior insular cortex regulation in autism spectrum disorders. Front Behav Neurosci 2015;9(38), doi:http://dx.doi.org/10.3389/fnbeh.2015.00038.

[18] Gibbard CR, Ren J, Skuse DH, Clayden JD, Clark CA. Structural connectivity of the amygdala in young adults with autism spectrum disorder. Hum Brain Mapp 2017;39(3):1270–82.

[19] Kana RJ, Uddin LQ, Kenet T, Chugani D, Muller R-A. Brain connectivity in autism. Front Hum Neurosci 2014;8:, doi:http://dx.doi.org/10.3389/fnhum.2014.00349.

[20] Gaigg SB. The interplay between emotion and cognition in autism Spectrum disorder: implications for developmental theory. Front Integr Neurosci 2012;6:, doi:http://dx.doi.org/10.3389/fnint.2012.00113.

[21] Moriguchi Y, Ohnishi T, Lane RD, Maeda M, Mori T, Nemoto K, et al. Impaired self-awareness and theory of mind: an fMRI study of mentalizing in alexithymia. Neuroimage 2006;32(3):1472–82.

[22] Gaigg SB, Cornell ASF, Bird G. The psychophysiological mechanisms of Alexithymia in autism Spectrum disorder. Autism 2016;22(2), doi:http://dx.doi.org/10.1177/1362361316667062.

[23] Milosavljevic B, Leno VC, Simonoff E, Baird G, Pickles A, Jones CRG, et al. Alexithymia in adolescents with autism Spectrum disorder: its relationship to internalising difficulties, sensory modulation and social cognition. J Autism Dev Disord 2016;46(4):1354–67, doi:http://dx.doi.org/10.1007/s10803-015-2670-8.

[24] Livingston LA, Livingston LM. Commentary: alexithymia, not autism, is associated with impaired interoception. Front Psychol 2016;7:, doi:http://dx.doi.org/10.3389/fpsyci.2016.01103.

[25] Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. J Am Acad Child Adolesc Psychiatry 2008;47(8):921–9.

[26] Lumley MA, Neely LC, Burger AJ. The assessment of alexithymia in medical settings: implications for understanding and treating health problems. J Pers Assess 2007;89(3):230–46.

[27] Baer RA, Smith GT, Hopkins J, Krietemeyer J, Toney L. Using self-report assessment methods to explore facets of mindfulness. Assessment 2006;13(1):27–45.

[28] Beresnevaite M. Exploring the benefits of group psychotherapy in reducing alexithymia in coronary heart disease patients: a preliminary study. Psychother Psychosom 2000;69(3):117–22.

[29] Bagby RM, Parker JDA, Taylor GJ. The twenty-item Toronto Alexithymia scale—I. Item selection and cross-validation of the factor structure. J Psychosom Res 1994;38(1):23–32. https://doi.org/10.1016/0022-3999(94)90005-1.

[30] Kooiman CG, Spinhoven P, Trijsburg RW. The assessment of alexithymia: a critical review of the literature and a psychometric study of the Toronto Alexithymia Scale-20. J Psychosom Res 2002;53(6):1083–90. https://doi.org/10.1016/S0022-3999(02)00348-3.

[31] Vorst HCM, Bermond B. Validity and reliability of the bermond–Vorst alexithymia questionnaire. Pers Individ Dif 2001;30(3):413–34. https://doi.org/10.1016/S0191-8869(00)00033-7.

[32] Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. J Clin Epidemiol 2009;62(10):1006–12. https://doi.org/10.1016/j.jclinepi.2009.06.005.

[33] Westwood H, Kerr-Gaffney J, Stahl D, Tchanturia K. Alexithymia in eating disorders: systematic review and meta-analyses of studies using the Toronto Alexithymia Scale. J Psychosom Res 2017;99:66–81.

[34] Cochrane, T. C. (2014). Review Manager 5.3: The Nordic Cochrane Centre.

[35] Berthoz S, Lalanne C, Crane L, Hill EL. Investigating emotional impairments in adults with autism spectrum disorders and the broader autism phenotype. Psychiatry Res 2013;208(3):257–64. https://doi.org/10.1016/j.psychres.2013.05.014.

[36] Arellano D, Rauh R, Krautheim B, Spicker M, Schaller UM, Helzle V, et al. Interactive testbed for research in autism—the SARA project. Univers Access Inf Soc 2017, doi:http://dx.doi.org/10.1007/s10209-016-0521-9.

[37] Beck AT, Ward CH, Mendelson MM, Mock JJ, Erbaugh JJ. An inventory for measuring depression. Arch Gen Psychiatry 1961;4(6):561–71, doi:http://dx.doi.org/10.1001/archpsyc.1961.01710120031004.

[38] Spielberger CD. *State-trait anxiety inventory (Form Y) manual*. Redwood City, CA: Mind Garden,; 1983.

[39] Müller J, Bühner M, Ellgring H. Is there a reliable factorial structure in the 20-item Toronto Alexithymia Scale? : a comparison of factor models in clinical and normal adult samples. J Psychosom Res 2003;55(6):561–8. https://doi.org/10.1016/S0022-3999(03)00033-3.

[40] Swift L, Stephenson R, Royce J. The 20-item Toronto Alexithymia Scale: validation of factor solutions using confirmatory factor analysis on physiotherapy out-patients. Psychol Psychother Theory Res Pract 2006;79(1):83–8, doi:http://dx.doi.org/10.1348/147608305X42875.

[41] Müller J, Bühner M, Ellgring H. The assessment of alexithymia : psychometric properties and validity of the Bermond–vorst alexithymia questionnaire. Pers Individ Dif 2004;37(2):373–91. https://doi.org/10.1016/j.paid.2003.09.010.

[42] Haviland MG, Louise Warren W, Riggs ML. An observer scale to measure alexithymia. Psychosomatics 2000;41(5):385–92. https://doi.org/10.1176/appi.psy.41.5.385.

[43] Mattila AK, Salminen JK, Nummi T, Joukamaa M. Age is strongly associated with alexithymia in the general population. J Psychosom Res 2006;61(5):629–35. https://doi.org/10.1016/j.jpsychores.2006.04.013.

[44] De Berardis D, Campanella D, Nicola S, Gianna S, Alessandro C, Chiara C, et al. The impact of Alexithymia on anxiety disorders: a review of the literature. Curr Psychiatry Rev 2008;4:80–6.

[45] Li S, Zhang B, Guo Y, Zhang J. The association between alexithymia as assessed by the 20-item Toronto Alexithymia Scale and depression: a meta-analysis. Psychiatry Res 2015;227(1):1–9. https://doi.org/10.1016/j.psychres.2015.02.006.

[46] White SW, Oswald D, Ollendick T, Scahill L. Anxiety in children and adolescents with autism Spectrum disorders. Clin Psychol Rev 2009;29(3):216–29, doi: http://dx.doi.org/10.1016/j.cpr.2009.01.003.

[47] Wigham S, Barton S, Parr JR, Rodgers J. A systematic review of the rates of depression in children and adults with high-functioning autism Spectrum disorder. J Ment Health Res Intellect Disabil 2017;10(4):267–87, doi:http://dx.doi.org/10.1080/19315864.2017.1299267.

[48] Tani P, Lindberg N, Joukamaa M, Nieminen-von Wendt T, von Wendt L, Appelberg B, et al. Asperger syndrome, Alexithymia and perception of sleep. Neuropsychobiology 2004;49(2):64–70.

[49] Schaller, U M., Rauh R. What difference does it make? implicit, explicit and complex social cognition in autism Spectrum disorders. J Autism Dev Disord 2017;47(4):961–79, doi:http://dx.doi.org/10.1007/s10803-016-3008-x.

[50] Lartseva A, Dijkstra T, Buitelaar JK. Emotional language processing in autism spectrum disorders: a systematic review. Front Hum Neurosci 2014;8:991, doi: http://dx.doi.org/10.3389/fnhum.2014.00991.

[51] Barnes JL, Lombardo MV, Wheelwright S, Baron-Cohen S. Moral Dilemmas Film Task: a study of spontaneous narratives by individuals with autism spectrum conditions. Autism Res 2009;2(3):148–56, doi:http://dx.doi.org/10.1002/aur.79.

[52] Downs A, Smith T. Emotional understanding, cooperation, and social behavior in high-functioning children with autism. J Autism Dev Disord 2004;34(6):625–35, doi:http://dx.doi.org/10.1007/s10803-004-5284-0.

[53] Gaigg SB, Bowler DM. Illusory memories of emotionally charged words in autism Spectrum disorder: further evidence for atypical emotion processing outside the social domain. J Autism Dev Disord 2009;39(7):1031–8, doi:http://dx.doi.org/10.1007/s10803-009-0710-y.

[54] Rieffe C, Meerum Terwogt M, Kotronopoulou K. Awareness of single and multiple emotions in high-functioning children with autism. J Autism Dev Disord 2007;37(3):455–65, doi:http://dx.doi.org/10.1007/s10803-006-0171-5.

[55] Begeer S, Koot HM, Rieffe C, Meerum Terwogt M, Stegge H. Emotional competence in children with autism: diagnostic criteria and empirical evidence. Dev Rev 2008;28(3):342–69. https://doi.org/10.1016/j.dr.2007.09.001.

[56] Samson AC, Huber O, Gross JJ. Emotion Regulation in Asperger's Syndrome and High-Functioning Autism. Emotion 2012;12(4):659–65, doi:http://dx.doi.org/10.1037/a0027975.

[57] Leweke F, Leichsenring F, Kruse J, Hermes S. Is alexithymia associated with specific mental disorders? Psychopathology 2012;45(1):22–8.

[58] Ferguson E. Personality is of central concern to understand health: towards a theoretical model for health psychology. Health Psychol Rev 2013;7(Suppl. 1):S32–70.

9.1 Supplementary Material

Table S1

Quality assessment of included studies

	Method		Recruitment							Exposure (Alexiythmia) Measure		Analysis			Results			Total quality score (max. 17)
Paper	**Addressed clearly focused issue?**	**Appropriate method?**	**ASD recruitment described?**	**ASD defined precisely?**	**ASD diagnoses confirmed?**	**Power or sample size calculation?**	**NT recruitment described?**	**NTs matched to ASD group?**	**Checked NT group for ASD?**	**TAS described?**	**Use of additional measures?**	**Confounding factors (comorbidities) measured?**	**Confounding factors accounted in analysis?**	**Analysis appropriate to design?**	**Do you believe the results?**	**Results applicable?**	**Results fit with other available evidence?**	
Arellano et al. 2017 (1)	Y	Y	N	N	N	N	N	Age, IQ	N	Y	Y	N	N	Y	Y	Y	Y	9
Murray et al. 2017 (2)	Y	Y	Y	Y	Y	N	Y	Age, gender, verbal ability	Y	Y	N	N	N	Y	Y	Y	Y	13
Schaller & Rauh. 2017 (3)	Y	Y	Y	Y	Y	N	Y	Age, non-verbal intelligence	Y	Y	N	N	N	Y	Y	Y	Y	13
Hoffmann et al. 2016 (4)	Y	Y	Y	Y	Y	N	Y	IQ, gender	Y	Y	N	N	N	Y	Y	Y	Y	13

Milosavljevic et al. 2016 (5)	Y	Y	Y	Y	Y	N	Y	Age, gender	Y	Y	N	Depression and anxiety	N (insufficient power in TD group)	Y	Y	Y	Y	14
Patil et al. 2016 (6)	Y	Y	Y	Y	Y	N	N	Age, gender, level of education	N	Y	N	Depression	N	Y	Y	Y	Y	12
Krach et al. 2015 (7)	Y	Y	N	Y	Y	N	N	Age, gender, verbal intelligence	Y	Y	N	N	N	Y	Y	Y	Y	11
Berthoz et al. 2013 (8)	Y	Y	Y	Y	Y	N	Y	Age, gender (accounted for in analysis)	N	Y	Y	Depression and anxiety	Y	Y	Y	Y	Y	15
Schneider et al. 2013 (9)	Y	Y	Y	Y	Y	N	N	Age, gender, education	Y	Y	N	Depression. Psychiatric comorbidities also excluded in study design	N	Y	Y	Y	Y	13

Heaton et al. 2012 (10)	Y	Y	Y	Y	Y	N	Y	Age, gender, intelligence	Y	Y	N	N	N	Y	Y	Y	Y	13
Samson et al. 2012 (11)	Y	Y	Y	Y	Y	N	Y	Age, gender, level of education	Y	Y	N	N	N	Y	Y	Y	Y	13
Katsyri et al. 2008 (12)	Y	Y	Y	Y	Y	N	Y	Age, gender	Y	Y	N	N	N	Y	Y	Y	Y	13
Silani et al. 2008 (13)	Y	Y	N	Y	Y	N	N	Age, gender, IQ	Y	Y	Y	N	N	Y	Y	Y	Y	12
Lombardo et al. 2007 (14)	Y	Y	N	Y	Y	N	N	Age, gender	Y	Y	N	N	N	Y	Y	Y	Y	11
Tani et al. 2004 (15)	Y	Y	Y	Y	Y	N	Y	Age, gender, intelligence, body mass index (BMI)	Y	Y	N	Depression	N	Y	Y	Y	Y	14

Chapter 10: Taste sensitivity in anorexia nervosa: A systematic review

Kinnaird, E., Stewart, C. & Tchanturia, K. (2018). Taste sensitivity in anorexia nervosa: A systematic review. *International Journal of Eating Disorders, 51*(8), 771-784. doi: 10.1002/eat.22886

Received: 19 February 2018 | Revised: 27 March 2018 | Accepted: 22 April 2018
DOI: 10.1002/eat.22886

WILEY

REVIEW

International Journal of EATING DISORDERS

Taste sensitivity in anorexia nervosa: A systematic review

Emma Kinnaird[1] | Catherine Stewart[1,2] | Kate Tchanturia[1,2,3]

[1]Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom
[2]South London and Maudsley NHS Foundation Trust, London, United Kingdom
[3]Ilia State University, Tbilisi, Georgia

Correspondence
Kate Tchanturia, Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
Email: kate.tchanturia@kcl.ac.uk

Funding Information
Swiss Anorexia Nervosa Foundation, Grant Number 58-16; UK Medical Research Council, Grant Number: MR/N013700/1; King's College London member of the MRC Doctoral Training Partnership in Biomedical Sciences

Abstract

Objective: There is evidence for altered processing of taste in anorexia nervosa, particularly in the areas of reward processing and hedonic sensitivity. However, research on whether people with anorexia nervosa identify taste stimuli accurately, known as taste sensitivity, has yielded mixed findings. The objective of this study was to synthesize the literature on taste sensitivity in this disorder to provide a basis for future discussion on whether altered taste sensitivity may be also implicated in wider atypical taste processing in anorexia.

Method: Electronic databases were searched systematically to identify published research examining taste sensitivity in anorexia. Search terms were "anorexia nervosa", or "eating disorder", combined with "taste". 18 studies met inclusion criteria.

Results: The review of the findings suggest that individuals with AN may experience reduced taste sensitivity that may improve following recovery. However, there was a significant variability in results across studies, potentially reflecting methodological problems including low sample sizes, experimental designs, and uncontrolled confounding variables. **Discussion:** This review suggests that altered taste sensitivity could represent a component in the wider altered taste processing observed in anorexia nervosa. However, the heterogeneity of findings highlight the need for future research to consider methodological issues raised by this review.

Resumen

Objetivo: Existe evidencia de una alteración en el procesamiento del gusto en la anorexia nervosa, particularmente en áreas del procesamiento de la recompensa y la sensibilidad hedónica. Sin embargo, la investigación sobre si las personas con anorexia nervosa identifican los estímulos del gusto con precisión, conocida como sensibilidad del gusto, ha arrojado resultados mixtos. El objetivo de este estudio fue sintetizar la literatura sobre la sensibilidad del gusto en este trastorno para proporcionar una base para la discusión futura sobre si la sensibilidad al gusto alterada puede estar implicada también en el procesamiento atípico, más amplio, en la anorexia.

Método: Se realizó una búsqueda sistemática en bases de datos electrónicas para identificar investigaciones publicadas que examinaron la sensibilidad del gusto en la anorexia. Los términos de búsqueda fueron "anorexia nervosa" o "trastorno alimentario", combinados con "gusto". Un total de 18 estudios cumplieron los criterios de inclusión.

Resultados: la revisión de los hallazgos sugiere que las personas con AN experimentaron una sensibilidad del gusto reducida que puede mejorar después de la recuperación. Sin embargo, hubo una variabilidad significativa en los resultados entre los estudios, lo que podría reflejar problemas metodológicos que incluyen tamaños de muestra pequeños, diseños experimentales y variables de confusión no controladas.

Discusión: Esta revisión sugiere que la sensibilidad alterada del gusto podría representar un componente en el procesamiento del gusto alterado más amplio observado en la anorexia nervosa. Sin embargo, la heterogeneidad de los hallazgos resalta la necesidad de que las investigaciones futuras consideren las cuestiones metodológicas planteadas por esta revisión.

KEYWORDS
anorexia nervosa, eating disorders, taste, taste perception, taste threshold

1 | INTRODUCTION

Taste plays a key role in eating behavior (Boesveldt & de Graaf, 2017). Our ability to sense the primary tastes of sweet, salt, umami (savory), bitter, and sour enables us to identify the nutritional quality of food (van Dongen, van den Berg, Vink, Kok, & de Graaf, 2011). It has also been suggested that fat should be considered as a primary taste (Mattes, 2011). Taste additionally informs how pleasurable we find different foods: sweet tastes are generally perceived as more pleasurable, whereas bitter tastes are seen as unpleasant (Steiner, Glaser, Hawilo, & Berridge, 2001). This closely influences what foods we choose to eat, and in what quantities: in adults, the majority of our nutritional intake comes from predominantly sweet foods (47%), with only 14% of our calorie intake coming from foods rated as sour or bitter (Mattes, 1985). Consequently, taste is key in informing whether we find food rewarding, which in turn drives our appetite and eating behaviors through the brain reward system (Rolls, 2015).

Significantly, it has been suggested that altered reward processing may contribute towards the key symptoms of anorexia nervosa (AN) (Kaye, Fudge, & Paulus, 2009). AN is a condition characterized by a persistent restriction of food intake (APA, 2013). Vitally, recently proposed hypotheses suggest that atypical responses to taste stimuli could contribute towards this characteristic restriction (Kaye, Wierenga, Bailer, Simmons, & Bischoff-Grethe, 2013). While taste is usually rewarding (Rolls, 2015), in individuals with AN restriction, rather than taste, becomes rewarding (Kaye et al., 2013), and tastes are perceived as less pleasant (Szalay et al., 2010). The exact mechanism behind this altered reward processing of taste is debated: one possibility is that individuals with AN have an altered sensitivity threshold when consuming pleasurable tastes (Kaye et al., 2013). It has also been proposed that the hedonic properties of taste stimuli (i.e., the extent to which someone likes a taste) remain intact but the motivation for the stimuli is reduced (Keating, Tilbrook, Rossell, Enticott, & Fitzgerald, 2012).

Therefore, a significant proportion of research documenting atypical taste processing in AN, particularly brain imaging-based studies, has focused on taste–reward processing and the associated areas of taste hedonics and motivation (see Keating et al., 2012, for review). However, atypical taste processing is not limited to hedonic or reward responses (McCrickerd & Forde, 2016). A closely related area is that of taste sensitivity, referring to how accurately and how intensely we identify different taste stimuli. Taste sensitivity is a broad term and has been measured in the literature using a number of different approaches. Taste sensitivity incorporates research on taste recognition thresholds (the minimum concentration at which an individual can identify a taste), taste detection thresholds (the minimum concentration at which an individual can discriminate a taste from water, or a neutral substance), and subjective perceived taste intensity (individual perception of the intensity of a given stimulus).

Taste sensitivity is mediated by taste receptors on the tongue: different individuals have subtle differences in taste receptors, and the density of taste papillae, that influence taste sensitivity—which in turn influences what foods we perceive as pleasurable and choose to eat (Grimm & Steinle, 2011). For example, individuals who display a heightened sensitivity to bitter tastes may avoid more bitter tasting foods (Keller, Steinmann, Nurse, & Tepper, 2002). Taste sensitivity can also be influenced by dietary experience or environment, with individuals perceiving salty tastes as less pleasurable after following a low-sodium diet (Bertino, Beauchamp, & Engelman, 1982). Consequently, atypical taste sensitivity has been implicated in a number of negative outcomes relating to eating behavior. This includes a loss of taste in the elderly contributing to malnutrition, (Schiffman & Graham, 2000), and an association between low taste sensitivity and obesity (Overberg, Hummel, Krude, & Wiegand, 2012). It has been hypothesized that atypical taste processing may contribute towards the restricted eating behaviors seen in anorexia nervosa (Frank, Shott, Keffler, & Cornier, 2016). Significantly, if taste sensitivity is dampened in AN, then this could contribute to the documented reduced reward appeal of taste stimuli in this population (Keating et al., 2012).

Consistent with this hypothesis are findings that individuals with AN exhibit a reduced number of taste papillae, which could potentially contribute to altered taste processing (Wockel, Hummel, Zepf, Jacob, & Poustka, 2007; Wockel, Jacob, Holtmann, & Poustka, 2008). Findings from neuropsychological studies also support the hypothesis that taste sensitivity perception could be altered in AN. Imaging studies suggest that individuals with AN suggest a different or reduced activation to taste stimuli in the insula compared to HC (Frank et al., 2016; Monteleone et al., 2017; Wagner et al., 2008). Similarly, a study using EEG techniques to investigate the effects of pleasant (sweet) and unpleasant (bitter) taste stimuli in individuals with AN compared to HC found that individuals with AN showed differing patterns of activation in response to the different stimuli compared to HC (Toth et al., 2004). Significantly, three of these studies used individuals either recovered from AN or of a normal weight, suggesting that altered taste processing could persist following weight restoration.

However, studies on whether taste sensitivity is implicated in AN have reached conflicting conclusions, potentially reflecting small sample sizes or different methods. Therefore, the aim of the current review is to explore and synthesize the current literature on taste sensitivity in AN.

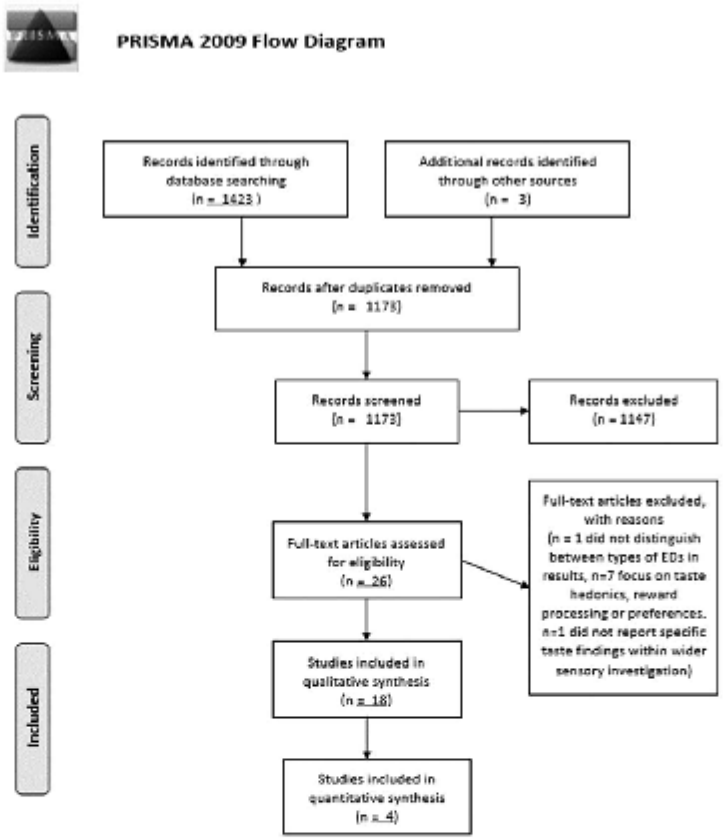


FIGURE 1 PRISMA diagram of study selection process

2 | METHOD

The systematic review was conducted in line with PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009).

2.1 | Eligibility criteria

Studies examining taste sensitivity (defined as the ability to perceive taste stimuli) in AN were included in this review. Only journal articles published in peer reviewed journals reporting data were considered; case studies, conference abstracts, theoretical, and opinion papers were excluded. Only papers published in English were included.

2.2 | Information sources and search

Electronic databases (PsychInfo, Scopus, PubMed, and Web of Science) were searched for papers up to and including January 2018. The search terms were anorexia nervosa, OR eating disorder, AND taste. Reference lists of published papers were also screened for eligible artides, yielding three additional papers.

2.3 | Selection

The selection process is summarized in Figure 1. Titles and abstracts of papers were screened for relevance to the topic of taste sensitivity. Papers exploring only reward–processing or hedonics of taste were not included. Full texts were obtained if the abstracts suggested that the paper was eligible, or if the eligibility was unclear. Any full texts which did not meet the inclusion criteria were excluded. Where papers reported multiple experiments or populations, only those sections relevant to AN and taste sensitivity are discussed.

Following study selection, data for the following variables was extracted independently from each paper: number of participants, age, BMI, gender, illness duration, diagnostic tool, how cases and controls were matched, exclusion criteria, design, methods, variables controlled for in analysis, and results. Where any information was unclear, the

authors were contacted for clarification. The wide variation in methods identified in this review prevented the identification of any single summary measure for meta-analysis, therefore only a qualitative synthesis is presented.

3 | RESULTS

The systematic review identified a total of 18 studies measuring taste sensitivity, summarized in Table 1. Two papers (Fernandez-Aranda et al., 2016; Ortega et al., 2016) were confirmed through correspondence with the authors to have reported on overlapping samples, with some of the cases and controls taking part in both studies. As this review did not incorporate a meta-analysis, both studies were retained in the review, with the limitations and implications of their overlapping sample highlighted in the results and the discussion.

The majority of studies used a case control design, with one study examining individuals with AN only (Casper, Kirschner, & Jacob, 1978), and one study comparing AN with bulimia nervosa (BN) but no healthy controls (HC) (Eiber, Berlin, de Brettes, Foulon, & Guelfi, 2002). Six studies additionally incorporated a longitudinal design, testing AN participants before treatment and/or following treatment or weight gain. Nine studies examined AN only, whilst nine additionally included either BN and/or obesity (OB). Only two studies included men in their analysis (Dazzi, De Nitto, Zambetti, Loriedo, & Ciofalo, 2013; Goldzak-Kunik, Friedman, Spitz, Sandler, & Leshem, 2012), with one study not reporting participant gender (Sunday & Halmi, 1990), and all others using only women.

Overall, the review identified studies covering the tastes of sweet, salt, umami, bitter, sour, and fat, although not all studies covered all six tastes. A variety of different methods were used in these studies to measure taste sensitivity, with the absence of any one standardized measure prohibiting meta-analysis. The studies used experimental approaches to measure the following aspects of taste sensitivity: taste recognition, taste detection, and subjective taste intensity. The results are summarized according to these four approaches.

3.1 | Taste recognition

A total of ten studies identified in this review approached taste sensitivity by measuring taste recognition. All studies measured the ability of participants to recognize the presence of sweet, sour, bitter and salty taste stimuli, except for one study (Goldzak-Kunik et al., 2012) which used commercially available preparations of different food and nonfood tastes (e.g., apple, chicken, toothpaste, coffee). Four studies (Aschenbrenner, Scholze, Joraschky, & Hummel, 2008; Dazzi et al., 2013; Fernandez-Aranda et al., 2016; Ortega et al., 2016) used taste strips to measure taste recognition abilities for sweet, bitter, salty, and sour tastes (Mueller et al., 2003). This method involves the placing of strips of filter paper soaked in different taste solutions at four different concentrations on the tongue. The taste strips are presented at increasing concentrations but in a randomized order of tastes. Subjects are then asked to identify the taste after each strip, giving an overall taste score. A higher score indicates better tasting recognition. Two studies used the closely related filter paper disc method (Nakai, Kinoshita, Koh, Tsuji, & Tsukada, 1987; Nozoe et al., 1996), measuring the ability to recognize sweet, bitter, salty, and sour at different concentration thresholds (Berling, Knutsson, Rosenblad, & von Unge, 2011). Circular filter paper discs are soaked in different taste solutions at five different concentrations and placed on the tongue. Tastes are presented in an ascending order of concentrations, until the participant correctly identifies the taste. A points scoring system is used: 1 represents a correct answer at the lowest threshold, 5 a correct answer at the highest threshold. A score of 6 is given if the subject is unable to correctly identify the taste at any threshold. Therefore, a higher score indicates poorer tasting recognition. Other studies used unique experimental approaches to measuring taste recognition. These four studies used a similar approach in principle to the taste strips or filter paper disc methods, where individuals were presented with solutions of different taste qualities, sometimes of varying concentrations, and asked to identify the taste (Casper et al., 1978; Casper, Kirschner, Sandstead, Jacob, & Davis, 1980; Goldzak-Kunik et al., 2012; Jirik-Babb & Katz, 1988).

Findings on taste recognition in AN were mixed. Goldzak-Kunik et al. (2012) found no differences across different food and nonfood tastes, but the fact that this was the only study to use food tastes (e.g., chocolate) as opposed to isolating specific taste qualities (e.g., sour, sweet), makes it difficult to compare and assess findings. The other nine studies assessed sweet, bitter, salty, and sour taste qualities, with inconsistent results. Six studies reported on the individual taste qualities: three out of these six studies found that individuals with AN had lower sweet taste recognition (Casper et al., 1978; Fernandez-Aranda et al., 2016; Nozoe et al., 1996), three found that those with AN had lower bitter taste recognition (Casper et al., 1978; Dazzi et al., 2013; Nozoe et al., 1996), two found that those with AN had lower salty taste recognition (Casper et al., 1978; Nozoe et al., 1996), and two found that those with AN had lower sour taste recognition (Casper et al., 1978; Nozoe et al., 1996). Of the five studies reporting overall taste scores only, all studies found that individuals with AN had lower overall scores compared to HC (Aschenbrenner et al., 2008; Casper et al., 1980; Dazzi et al., 2013; Nakai et al., 1987; Nozoe et al., 1996).

Therefore, whilst the literature suggests that overall taste recognition may be lowered in individuals with AN compared to HC, studies are inconsistent on exactly which taste qualities are affected. To an extent this may reflect methodological issues. Sample power across the studies were typically small, with only one study using sample sizes of over $n = 30$ in every group (Fernandez-Aranda et al., 2016; Ortega et al., 2016 discounted due to the sample overlapping with Fernandez-Aranda). Additionally, unlike many of the studies in this review, Fernández-Aranda et al. controlled for a number of potential variables in their study design, including smoking and medication use. Nonetheless, that a subsequent study using a similar design and an overlapping sample found no significant differences highlights the difficulty in replicating these findings (Ortega et al., 2016).

Moreover, not all studies controlled for confounding variables in their design or analysis. Only one study examining taste recognition distinguished between those with restrictive AN (AN-R) and binge/purge AN (AN-BP), with Aschenbrenner et al. (2008) including only

TABLE 1 Summary of studies included in systematic review

Methodology	Paper	Participants	Age (years) Mean (*SD*)	Mean BMI (*SD*)	Illness duration (years) Mean (*SD*)	Design	Equipment	Taste qualities Measured	Controlled variables (in exclusion, design or analysis)	Results
Taste recognition	Fernández-Aranda et al. (2016)	AN (both R and B/P) = 64 HC = 80	24.0 (5.3) 22.6 (2.9)	17.4 (1.4) 21.6 (2.9)	5.5 (5.3)	Case–control	Taste recognition (taste strips)	Sweet, bitter, salty, sour	Age, gender, illness or medication that might affect taste, depression, smoking, contraceptive use, diabetes	**Sweet**: Lower sweet detection in AN (3.10 [0.15]) vs. younger HC (3.47 [0.13]) **Bitter**: No difference **Salty**: No difference **Sour**: No difference
	Ortega et al. (2016)	AN = 52 OB = 72 HC = 86	Overall sample 34 (12)	16.5 (1.3) 41.1 (7.7) 21.5 (2.8)		Case–control	Taste recognition (taste strips)	Sweet, bitter, salty, sour	Age, gender, illness or medication that might affect taste	**Sweet**: No difference **Bitter**: No difference **Salty**: No difference **Sour**: No difference
	Dazzi et al. (2013)	AN (both R and B/P) = 18 BN = 19 HC = 19	Overall sample 26.55 (6.29)	15.74 22.07 21.37		Case–control	Taste recognition (taste strips)	Sweet, bitter, salty, sour	Age, medical conditions affecting taste	**Sweet**: No difference **Bitter**: Lower bitter detection in AN compared to HC (6.33 [1.18] vs. 7.37 [0.91]) **Salty**: No difference **Sour**: No difference **Overall score**: Lower taste score in AN compared to HC (24.67 [3.67] vs. 27.79 [2.60])
	Goldzak-Kurnik et al. (2012)	AN = 15 HC = 15	15.8 (0.34) 15.0 (0.48)	17.2 (0.50) 19.4 (0.58)		Case–control	A selection of food tastes and nonfood tastes were prepared in concentrations of varying intensity and sprayed onto tongue. Scored on identification	Food tastes (apple, chocolate, cherry, chicken, and sweet vanilla) and nonfood tastes (toothpaste, coffee, chewing gum, soap, and infant vitamin drops)	Gender, school grade	**Overall score**: No significant differences across groups. Improved recognition of apple in AN, poorer recognition of chicken compared to HC
	Aschenbrenner et al. (2008)	AN-R = 16 BN = 24 HC = 23	24.5 (4.0) 24.3 (4.6) 24.5 (4.8)	14.94 (2.05) 19.64 (3.05) 21.12 (2.20)		Case–control, longitudinal (admission/discharge)	Taste recognition (taste strips)	Overall taste scores given only	Gender, medication, medical conditions that might affect taste	**Overall score**: AN taste score on admission significantly lower compared to HC (22.25 [5.99] vs. 27.52 [3.06]). Significant improvement upon discharge (23.91 [3.65]). Taste scores correlated with BMI
	Nozoe et al. (1996)	AN = 9 HC = 6	19.3 (3.8) 21.8 (1.5)		21.4 (11.1) months	Case–control, longitudinal (admission,	Filter paper disc method	Sweet, bitter, salty, sour	No systemic, endocrine, or central nervous	**Sweet**: AN significantly lower compared to HC upon admission (exact scores not given).

(Continues)

TABLE 1 (Continued)

Methodology	Paper	Participants	Age (years) Mean (*SD*)	Mean BMI (*SD*)	Illness duration (years) Mean (*SD*)	Design	Equipment	Taste qualities Measured	Controlled variables (in exclusion, design or analysis)	Results
						1 week after initiation of treatment, when food intake reached 1600 kcal a day, discharge)			system illness, medication, vomiting prior to admission, age, gender	Did not significantly improve until discharge **Bitter**: AN significantly lower compared to HC upon admission (exact scores not given). Significantly improved when food intake increased **Salty**: AN significantly lower compared to HC upon admission (exact scores not given). Did not significantly improve until discharge **Sour**: AN significantly lower compared to HC upon admission (exact scores not given). Significantly improved when food intake increased **Overall score**: AN exhibited significantly poorer taste sensitivity upon admission compared to HC (97 [19] vs. 57 [7]). Significant improvement achieved when food intake increased (55 [15]) Significant improvement at discharge (46 [13]) Taste scores not correlated with BMI or illness duration
	Jirik-Babb and Katz (1988)	AN = 9 BN = 5 HC = 7				Case–control	Measuring recognition at different concentrations in distilled water	Sweet, bitter, salty, sour	Gender	**Sweet**: No difference **Bitter**: No difference **Salty**: No difference **Sour**: No difference
	Nakai et al. (1987)	AN = 23 BN = 13 HC = 18	19.3 (4.0) 21.5 (4.0) 22.0 (1.6)			Case control, longitudinal (7 AN re-tested following treatment).	Filter paper disc method	Overall taste scores given only (tested sweet, bitter, salty, sour)	Gender, no taste altering medication	**Overall score**: AN scores significantly lower compared to HC (9.9 [2.7] vs. 15.0 [1.8]). Improved following treatment but not to HC levels
	Casper et al. (1980)	AN = 30 HC = 10	19.1 (4.4) 22		2.3 (2.7)	Case control, longitudinal (7 AN re-tested fol-	Measuring recognition at different concentrations in distilled	Overall taste scores given only (tested sweet, bitter,	Gender	**Overall score**: AN scores significantly lower compared to HC (11.8 [4.2] vs. 17.1 [1.4]).

(Continues)

TABLE 1 (Continued)

Methodology	Paper	Participants	Age (years) Mean (*SD*)	Mean BMI (*SD*)	Illness duration (years) Mean (*SD*)	Design	Equipment	Taste qualities Measured	Controlled variables (in exclusion, design or analysis)	Results
						lowing discharge).	water	salty, sour)		Improved significantly following discharge but not to HC levels No correlation with zinc plasma levels
	Casper et al. (1978)	AN = 13					Forced choice-three stimulus drop technique.	Sweet, bitter, salty, sour	Gender	**Sweet**: Reduced recognition in AN **Bitter**: Reduced recognition in AN **Salty**: Reduced recognition in AN **Sour**: Reduced recognition in AN Participants with lower taste recognition had reduced plasma zinc levels, but some participants with normal taste recognition showed similarly lowered levels
Taste Detection	Eiber et al. (2002)	AN-R = 20 AN-BP = 20 BN = 20	23.3 (4.8) 26.4 (5.5) 27.5 (5.8)	15.7 (1.6) 16.1 (1.3) 22.7 (2.7)			Sweet taste perception threshold test: administered different sucrose solutions, reported when perceived sweet taste	Sweet	Gender, no taking psychotropic medication, no other DSM-IV axis I diagnosis, no receiving parenteral nutrition, no medical condition interfering with taste, BMI	**Sweet**: AN-R detection threshold significantly higher compared to AN-BP/BN (no difference). Difference disappeared when BMI included as covariate
	Nakai et al. (1987)	AN = 23 BN = 13 HC = 18	19.3 (4.0) 21.5 (4.0) 22.0 (1.6)			Case control, longitudinal (7 AN re-tested following treatment).	Filter paper disc method	Sweet, bitter, salty, sour	Gender, no taste altering medication	**Sweet**: Reduced detection in AN **Bitter**: Reduced detection in AN **Salty**: Reduced detection in AN **Sour**: Reduced detection in AN
	Casper et al. (1980)	AN = 30 HC = 10	19.1 (4.4) 22		2.3 (2.7)	Case control, longitudinal (7 AN re-tested following discharge).	Measuring detection at from distilled water	Sweet, bitter, salty, sour	Gender	**Sweet**: Least affected in AN **Bitter**: Reduced detection in AN **Salty**: Less affected in AN **Sour**: Reduced detection in AN
	Lacey et al. (1977)	AN = 6 HC = 6	20.5 (5.1) 21.1 (6.9)			Case–control	Forced choice method: discri-	Sweet	Age, gender, caloric intake	**Sweet**: No significant difference between AN (0.49 [0.50]) and

(Continues)

TABLE 1 (Continued)

Methodology	Paper	Participants	Age (years) Mean (SD)	Mean BMI (SD)	Illness duration (years) Mean (SD)	Design	Equipment	Taste qualities Measured	Controlled variables (in exclusion, design or analysis)	Results
							minating between distilled water and sucrose water at varying concentrations			HC (0.74 [0.50]), although AN trending lower than HC. Taste threshold of both anorectics and controls related to calorific intake
Subjective Taste Intensity	Frank et al. (2016)	AN-R = 21 AN-R Rec = 19 BN = 20 OB = 19 HC = 27	22.9 (6.1) 27.0 (5.3) 25.2 (5.3) 28.2 (8.1) 26.2 (7.0)	16.0 (1.1) 20.2 (1.1) 22.6 (5.7) 34.7 (4.6) 21.5 (1.4)		Case–control	Rating intensity of different concentrations	Sweet	Gender	**Sweet:** No difference
	Schebendach et al. (2015)	AN (both R and B/P) = 25 HC = 25	27.2 (7.8) 23.3 (3.5)	17.3 (2.0) 21.1 (1.6)		Case–control	Participants rated fat content of different cream cheese samples in their mouths	Fat	Gender, no smoking, age	**Fat:** No difference
	Goldzak-Kunik et al. (2012)	AN = 15 HC = 15	15.8 (0.34) 15.0 (0.48)	17.2 (0.50) 19.4 (0.58)		Case–control	Tastes prepared in concentrations of varying intensity and sprayed onto tongue Participants rated intensity	Sweet, bitter, salty, sour, umami	Gender, school grade	**Sweet:** No difference **Bitter:** No difference **Salty:** No difference **Sour:** No difference **Umami:** No difference
	Klein et al. (2010)	AN (both R and B/P) = 24 HC = 24	25.21 (1.08) 26.70 (1.4)	16.08 (0.25) 21.01 (0.66)	8.3 (1.4)	Case–control	Modified sham feeding technique to measure intake of five different solutions with differing levels of sweetness	Sweet	Gender	**Sweet:** No difference
	Simon et al. (1993)	AN-R = 11 HC = 14	26.8	14 20.7	8.9	Case–control	Rating intensity of soft cheese stimuli modified for sweetness	Sweet	Gender, type of AN	**Sweet:** No difference
	Sunday and Halmi (1990)	AN-R = 48 AN-B/P = 36 BN = 42 HC = 26	AN-R = 48 AN-B/P = 36 BN = 42 HC = 26	18.94 (0.85) 21.31 (0.80) 21.51 (0.89) 19.27 (0.24)	14.68 (0.27) 16.30 (0.36) 20.75 (0.31) 20.91 (0.33)	Case–control, longitudinal (pre and post treat-	Rated sweetness and fattiness intensity of different dairy so-	Sweet, fat	Medication, type of AN	**Sweet:** No differences across groups Perceived sweetness reduced following treatment

(Continues)

TABLE 1 (Continued)

Methodology	Paper	Participants	Age (years) Mean (*SD*)	Mean BMI (*SD*)	Illness duration (years) Mean (*SD*)	Design	Equipment	Taste qualities Measured	Controlled variables (in exclusion, design or analysis)	Results
						ment)	lutions with varying levels of sweetness and fat. Also water taste test with varying levels of sweetness			Fat: AN-BP rated fat more intensely compared to HC Perceived fattiness reduced following treatment in AN-B/P only
	Jirik-Babb and Katz (1988)	AN = 9 BN = 5 HC = 7				Case–control	Measuring magnitude estimation at different concentrations in distilled water	Sweet, bitter, salty, sour	Gender, duration of illness	Sweet: No difference Bitter: Lower intensity ratings for AN compared to HC Salty: Lower intensity ratings for AN compared to HC Sour: Lower intensity ratings for AN compared to HC Duration of illness correlated with lower intensity ratings
	Drewnowski et al. (1987)	AN-R = 12 AN-BP = 13 BN = 7 HC = 16	16.3 (2.2) 19.5 (4.2) 19.4 (2.5) 19.1 (0.8)	14.8 (1.6) 16.2 (2.3) 21.3 (2.0) 21.1 (1.6)		Case control (longitudinal, admission and post 3 week maintenance of target weight)	Rating sweetness and fat content of dairy stimuli with varying levels of sucrose and fat	Sweet, fat	Gender	Sweet: No difference Fat: No difference

those with AN-R in their study. This is significant as taste could be potentially adversely affected by repeated vomiting (Rodin, Bartoshuk, Peterson, & Schank, 1990). Some other studies highlighted that they did not differentiate between people with AN-R and AN-BP in their analysis, but many did not specify if they included both subgroups, reporting the sample only as "AN". Moreover, where studies did specify the inclusion of those with AN-BP it was often unclear whether the diagnosis of purging was based on vomiting, or, for example, the use of laxatives or fasting. In line with this, only one study specified vomiting as an exclusion criteria (Nozoe et al., 1996). In addition, only a minority of studies controlled for smoking in their study design or analysis (Fernandez-Aranda et al., 2016; Ortega et al., 2016). This is despite research suggesting that smokers exhibit lower taste sensitivity compared to nonsmokers (Chéruel, Jarlier, & Sancho-Garnier, 2017).

Where studies did examine the role of potentially confounding variables, this was instructive in highlighting potential mechanisms behind these differences in taste recognition. Aschenbrenner et al. (2008) found that overall taste scores correlated with BMI. Although another study found that taste recognition did not correlate with BMI, this used a comparably small sample size (AN $n = 9$) (Nozoe et al., 1996). In addition, studies that employed a longitudinal design, measuring individuals with AN both upon admission and discharge, found that taste recognition improved following treatment and discharge, although not normalizing to HC levels (Aschenbrenner et al., 2008; Casper et al., 1980; Nakai et al., 1987; Nozoe et al., 1996). Therefore, these findings suggest that lower taste sensitivity in AN could potentially improve, but not normalize, with treatment and/or weight restoration. However, the exact mechanisms behind these improvements remain unclear. Only one study controlled for illness duration in the analysis, finding that illness duration did not correlate with taste sensitivity (Nozoe et al., 1996). However, this may again reflect that study's small sample size.

3.2 | Taste detection

Four studies measured taste detection thresholds, defined as the minimum concentration at which an individual can discriminate the presence of a taste stimulus from water, or a neutral substance (Casper et al., 1980; Eiber et al., 2002; Lacey, Stanley, Crutchfield, & Crisp, 1977; Nakai et al., 1987).

Whilst Casper et al.(1980) and Nakai et al.(1987) measured taste detection of sweet, bitter, salty, and sour taste qualities, finding reduced detection in people with AN, reporting standards were low, with both studies reporting reduced detection without giving exact scores.

Although Eiber et al. (2002) only measured sweet taste detection, the methods used in this paper was comparatively stronger. Despite not using a HC group as comparison, Eiber et al. (2002) was the only paper examining taste detection to distinguish between those with AN-R and AN-BP, finding that the detection threshold for those with AN-R was significantly higher compared to those with AN-BP and bulimia (BN). However, this difference disappeared when BMI was introduced as a covariate, suggesting that sweet taste detection thresholds may be related to a lower BMI. By comparison, Lacey et al. (1977) found no significant differences between the sweet detection thresholds of those with AN and HC. However, this was with a comparatively much smaller sample size, with $n = 6$ in each group compared to $n = 20$ in each group in Eiber et al. Nonetheless, Lacey et al. did find that taste thresholds of both those with AN and HC on a low calorie diet were comparatively lower compared to those on a high calorie diet, suggesting a relationship between taste sensitivity and diet.

3.3 | Subjective taste intensity

Six studies measured perceptions of taste intensity by presenting participants with stimuli varying on a certain sweetness and/or fat and asking them to rate and compare the different stimuli on the intensity of this quality (Drewnowski, Halmi, Pierce, Gibbs, & Smith, 1987; Frank et al., 2016; Klein, Schebendach, Gershkovich, Smith, & Walsh, 2010; Schebendach et al., 2014; Simon, Bellisle, Monneuse, Samuelbjeunesse, & Drewnowski, 1993; Sunday & Halmi, 1990). Two additional studies measured salty, bitter, and sour taste qualities in addition to sweet: Goldzak-Kunik et al.(2012), and Jirik-Babb and Katz (1988), presented these four different taste solutions in different concentrations, and asked participants to rate their intensity.

Different studies used different stimuli to explore subjective taste intensity. Three studies presented participants with tastes distilled at different concentrations in water (Frank et al., 2016; Goldzak-Kunik et al., 2012; Jirik-Babb & Katz, 1988). One study gave participants cherry Kool Aid solutions sweetened with varying concentrations of aspartame (Klein et al., 2010). The four other studies presented participants with dairy stimuli altered to have different concentrations of sweetness and/or fat (e.g., Schebendach et al., 2014; used fat free, low fat and regular types of the same cream cheese brand).

Specifically looking at sweetness and/or fat perception only, Drewnoski et al. (1988), Frank et al.(2016), Klein et al. (2010), Schebendach et al. (2014), Simon et al. (1993), and Sunday and Halmi (1990) and found that individuals with AN were equally as sensitive as HC in perceiving sweetness or fat. However, Sunday and Halmi (1990) did find that individuals with AN-BP perceived solutions as fattier compared to controls before treatment, a difference which resolved following treatment. A key strength of this study was its sample size: whilst the other studies using this approach typically used small sample sizes, Sunday and Halmi (1990) included a total of 132 participants.

Of the two studies examining sweet, bitter, salty, and sour tastes, Goldzak-Kunik et al. (2012) found no differences in perceived intensity across these taste qualities. Jirik-Babb and Katz (1988) found no difference in perceived intensity of sweetness, though did find evidence for lower intensity ratings of bitter, salty, and sour tastes in those with AN compared to HC.

Consequently, the literature strongly suggests that perceived fat and sweetness intensity is not reduced or increased in AN when compared with HC, although there is some evidence that perceived fat intensity may be specifically increased in those with AN-BP (Sunday & Halmi, 1990). This same study also suggests that this may resolve following treatment. These findings are supported by the fact that the majority of studies examining taste intensity did account for

differences between AN subgroups, either dividing them into separate groups in the analysis, or specifying which subtype was included in the study design (typically AN-R). For bitter, salty, and sour tastes, the literature is both limited and conflicting, with small sample sizes (total AN group is only $n = 24$ across both studies) preventing further conclusions.

4 | DISCUSSION

The overall findings of this systematic review indicate that the literature on taste sensitivity in AN is characterized by significant heterogeneity, potentially reflective of methodological limitations. Findings on subjective taste intensity were most consistent, with most studies suggesting that there are no differences in perceived sweetness and/or fat intensity between those with AN and HC. The majority of studies on taste recognition and taste detection suggested reduced thresholds in those with AN, although the significant disagreement across studies prevents any firm conclusions. Significantly, in studies that did find reduced taste recognition in AN and additionally incorporated a longitudinal design, results suggested that taste recognition may improve following treatment and discharge, but not normalize to HC levels.

This to an extent may indicate methodological limitations: sample sizes used across studies were often low, with the lowest study using $n = 6$ per group (Lacey et al., 1977). Even where two studies used overlapping samples and the same experimental design, these found conflicting results, with one study reporting no differences (Ortega et al., 2016), and the other reporting lower sweet taste detection (Fernandez-Aranda et al., 2016). Moreover, only a minority of studies accounted for variables which are known to affect taste, including smoking or repeated vomiting. In addition to methodological limitations, the variation in findings could also indicate that taste sensitivity in AN is characterized by a wide heterogeneity across individuals. If taste sensitivity does vary across individuals with AN then this suggests the need to control and identify potential variables in study design and analysis: for example, studies in this review suggest that taste sensitivity could be related to BMI, with a lower BMI relating to reduced taste sensitivity (Aschenbrenner et al., 2008; Eiber et al., 2002). Similarly, the findings that reduced taste recognition in people with AN may improve following weight restoration in recovery also require further research to isolate the potential causes of this improvement. The studies included in this review only explored this aspect from a longitudinal perspective, following the same patients from their illness state to weight restoration: future research could compare ill and remitted individuals to explore this issue further.

Only a minority of studies in this review explored potential biological mechanisms behind altered taste sensitivity in AN. Although Casper et al. (1978) found some evidence that reduced zinc plasma levels could be related to lower taste recognition in AN, a subsequent study with a larger sample size (Casper et al. 1980) did not support this finding. Moreover, despite evidence that the ability to taste some bitter compounds (e.g., 6-n-propylthiouracil, or "PROP") is genetically determined, no study controlled for the potential of genetic variables, potentially contributing to the heterogeneity of results (Tepper, Banni, Melis, Cmjar, & Tomassini Barbarossa, 2014). Similarly, although a number of hormones, including leptin, cholecystokinin (CCK), and ghrelin, have been implicated in taste sensitivity, the reviewed studies did not assess hormone levels (Cai et al., 2013; Han, Keast, & Roura, 2017; Yoshida et al., 2017). Significantly, these hormones are known to be altered in AN, suggesting that future research could explore the role of these biological factors in taste sensitivity in this population (Atalayer, Gibson, Konopacka, & Geliebter, 2013; Cuntz et al., 2013; Hebebrand, Muller, Holtkamp, & Herpertz-Dahlmann, 2006). Therefore, this systematic review highlights the need for controlled experimental designs in future research in taste sensitivity, with consideration for potential confounding variables, to illuminate the conflicting findings of previous research in this area.

The suggestion of some of the literature reviewed in this paper that individuals with AN may have reduced sensitivity resonate with previous research on taste and reward processing in this illness. Previous literature suggests that, unlike HC, individuals with AN may not process tastes as rewarding, contributing towards the characteristic symptom of food restriction (Kaye et al., 2013; Rolls, 2015). If taste sensitivity is indeed reduced in AN, then this could contribute towards this mechanism by reducing the pleasantness of food and so minimizing its reward value (Steiner et al., 2001). Consistent with this possibility is research suggesting that individuals with AN perceive tastes as less pleasurable (Szalay et al., 2010), although the research on this topic is again conflicting (Keating et al., 2012). If taste sensitivity is indeed reduced in AN, this could suggest that individuals with AN could benefit from interventions used to combat reduced taste sensitivity in other populations, such as introducing flavor-enhanced foods into their diet to promote palatability and intake, or using zinc supplementation (Najafizade et al., 2013; Schiffman & Graham, 2000).

Interestingly, the hypothesis that individuals with AN have lowered taste sensitivity, or no differences in taste sensitivity compared to HC as suggested by the reviewed literature, conflicts with self-reports of perceived heightened sensitivity in AN. Individuals with AN self-report being hyper-sensitive to taste stimuli, particularly sweetness or fat, and this may persist following weight restoration (Brand-Gothelf et al., 2016; Pierce & Halmi, 1988). The findings of this study suggesting that there are in fact no differences in the perception of sweetness or fat intensity between people with AN and HC indicates that the documented aversion to this stimuli in individuals with AN reflects subjective perception, rather than objective taste alterations. Instead, sweetness and fat avoidance in AN may instead be driven by the cognitive resistance and inflexibility documented in this population (Lang, Stahl, Espie, Treasure, & Tchanturia, 2014; Tchanturia et al., 2012; Westwood, Stahl, Mandy, & Tchanturia, 2016).

Moreover, these findings indicate a potential conflict between self-perceived (heightened) and actual (lowered) sensitivity to taste stimuli that closely resembles sensory prediction errors documented in AN in the field of interoceptive processing: individuals with AN appear to self-report heightened levels of interoceptive sensitivity, whilst in fact exhibiting lower sensitivity on experimental measures (Khalsa et al., 2015; Khalsa & Lapidus, 2016). These interoceptive prediction

errors have been associated with heightened anxiety and can act as a potent motivation to avoid the triggering stimulus- such as food or tastes (Kaye et al., 2004; Paulus & Stein, 2010). This could indicate that sensory prediction errors in AN are not isolated to interoception, but also exist in other, exteroceptive, sensory domains, such as taste, warranting further research.

5 | LIMITATIONS

The key limitation of this systematic review was its inability to carry out a meta-analysis on these findings, due to the lack of any consistent summary measure across the included studies. This reflected a wider difficulty in this review: it is likely that the wide variation in findings found in this review to an extent reflects the variation in methods used across studies, making direct comparisons difficult. However, this highlights the need for specific and highly controlled research designs in this field in the future, in order to both produce more reliable findings and to make comparison across studies easier.

6 | CONCLUSIONS

This systematic review suggests that individuals with AN could experience lowered taste sensitivity. However, the previous literature on this topic is highly variable and characterized by methodological limitations. Future research in this area should consider the methodological issues raised by this review, including low sample sizes, experimental designs, and uncontrolled confounding variables, to explore whether these previous findings are replicable. Further research could also explore the potential mechanisms behind altered taste sensitivity in AN, including changes in BMI, diet, and biological factors.

ACKNOWLEDGMENTS

This paper represents independent research. KT would like to acknowledge financial support from MRC and MRF Child and Young Adult Mental Health—the underpinning etiology of self-harm and eating disorders and Swiss Anorexia Nervosa Foundation, Grant Number 58-16. EK is supported by the UK Medical Research Council, Grant Number: MR/N013700/1 and is a King's College London member of the MRC Doctoral Training Partnership in Biomedical Sciences.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

ORCID

Emma Kinnaird http://orcid.org/0000-0002-6821-8386
Kate Tchanturia http://orcid.org/0000-0001-8988-3265

REFERENCES

Aschenbrenner, K., Scholze, N., Joraschky, P., & Hummel, T. (2008). Gustatory and olfactory sensitivity in patients with anorexia and bulimia in the course of treatment. *Journal of Psychiatric Research*, *43*(2), 129–137. https://doi.org/10.1016/j.jpsychires.2008.03.003

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5 Ed.). Arlington, VA: American Psychiatric Publishing.

Atalayer, D., Gibson, C., Konopacka, A., & Geliebter, A. (2013). Ghrelin and eating disorders. *Progress in Neuro-Psychopharmacology & Biological Psychiatry*, *40*, 70–82. https://doi.org/10.1016/j.pnpbp.2012.08.011

Berling, K., Knutsson, J., Rosenblad, A., & von Unge, M. (2011). Evaluation of electrogustometry and the filter paper disc method for taste assessment. *Acta Oto-Laryngologica*, *131*(5), 488–493. https://doi.org/10.3109/00016489.2010.535850

Bertino, M., Beauchamp, G., & Engelman, K. (1982). Long-term reduction in dietary sodium alters the taste of salt. *American Journal of Clinical Nutrition*, *36*(6), 1134–1144.

Boesveldt, S., & de Graaf, K. (2017). The differential role of smell and taste for eating behavior. *Perception*, *46*(3–4), 307–319. https://doi.org/10.1177/0301006616685576

Brand-Gothelf, A., Parush, S., Eitan, Y., Admoni, S., Gur, E., & Stein, D. (2016). Sensory modulation disorder symptoms in anorexia nervosa and bulimia nervosa: A pilot study. *International Journal of Eating Disorders*, *49*(1), 59–68.

Cai, H., Cong, W-N., Daimon, C. M., Wang, R., Tschöp, M. H., Sévigny, J., … Maudsley, S. (2013). Altered lipid and salt taste responsivity in ghrelin and GOAT null mice. *Plos One*, *8*(10), e76553. https://doi.org/10.1371/journal.pone.0076553

Casper, R. C., Kirschner, B., & Jacob, R. A. (1978). Zinc and copper status in anorexia nervosa. *Psychopharmacology Bulletin*, *14*(3), 53–55.

Casper, R. C., Kirschner, B., Sandstead, H. H., Jacob, R. A., & Davis, J. M. (1980). An evaluation of trace-metals, vitamins, and taste function in anorexia-nervosa. *American Journal of Clinical Nutrition*, *33*(8), 1801–1808.

Chéruel, F., Jarlier, M., & Sancho-Garnier, H. (2017). Effect of cigarette smoke on gustatory sensitivity, evaluation of the deficit and of the recovery time-course after smoking cessation. *Tobacco Induced Diseases*, *15*(1), 15. https://doi.org/10.1186/s12971-017-0120-4

Cuntz, U., Enck, P., Frühauf, E., Lehnert, P., Riepl, R. L., Fichter, M. M., & Otto, B. (2013). Cholecystokinin revisited: CCK and the hunger trap in anorexia nervosa. *Plos One*, *8*(1), e54457. https://doi.org/10.1371/journal.pone.0054457

Dazzi, F., De Nitto, S., Zambetti, G., Loriedo, C., & Ciofalo, A. (2013). Alterations of the olfactory-gustatory functions in patients with eating disorders. *European Eating Disorders Review*, *21*(5), 382–385. https://doi.org/10.1002/erv.2238

Drewnowski, A., Halmi, K. A., Pierce, B., Gibbs, J., & Smith, G. P. (1987). Taste and eating disorders. *American Journal of Clinical Nutrition*, *46*(3), 442–450.

Drewnowski, A., Pierce, B., & Halmi, K. A. (1988). Fat aversion in eating disorders. *Appetite*, *10*(2), 119–131.

Eiber, R., Berlin, I., de Brettes, B., Foulon, C., & Guelfi, J. D. (2002). Hedonic response to sucrose solutions and the fear of weight gain in patients with eating disorders. *Psychiatry Research*, *113*(1–2), 173–180. https://doi.org/10.1016/s0165-1781(02)00232-9

Fernández-Aranda, F., Agüera, Z., Fernández-García, J. C., Garrido-Sanchez, L., Alcaide-Torres, J., Tinahones, F. J., … Casanueva, F. F. (2016). Smell-taste dysfunctions in extreme weight/eating conditions: Analysis of hormonal and psychological interactions. *Endocrine*, *51*(2), 256–267. https://doi.org/10.1007/s12020-015-0684-9

Frank, G. K., Shott, M. E., Keffler, C., & Comier, M.-A. (2016). Extremes of eating are associated with reduced neural taste discrimination. *International Journal of Eating Disorders*, *49*(6), 603–612.

Goldzak-Kunik, G., Friedman, R., Spitz, M., Sandler, L., & Leshem, M. (2012). Intact sensory function in anorexia nervosa. *American Journal of Clinical Nutrition*, *95*(2), 272–282. https://doi.org/10.3945/ajcn.111.020131

Grimm, E. R., & Steinle, N. I. (2011). Genetics of eating behavior: Established and emerging concepts. *Nutrition Reviews*, *69*(1), 52–60. https://doi.org/10.1111/j.1753-4887.2010.00361.x

Han, P., Keast, R. S. J., & Roura, E. (2017). Salivary leptin and TAS1R2/TAS1R3 polymorphisms are related to sweet taste sensitivity and carbohydrate intake from a buffet meal in healthy young adults. *British Journal of Nutrition*, *118*(10), 763–770. https://doi.org/10.1017/S0007114517002872

Hebebrand, J., Muller, T. D., Holtkamp, K., & Herpertz-Dahlmann, B. (2007). The role of leptin in anorexia nervosa: Clinical implications. *Molecular Psychiatry*, *12*(1), 23. https://doi.org/10.1038/sj.mp.4001909

Jirik-Babb, P., & Katz, J. L. (1988). Impairment of taste perception in anorexia-nervosa and bulimia. *International Journal of Eating Disorders*, *7*(3), 353–360. https://doi.org/10.1002/1098-108x(198805)7:3<353::aid-eat2260070306>3.0.co;2-y

Kaye, W. H., Bulik, C. M., Thornton, L., Barbarich, N., Masters, K., & Price FDN Collaborative Group. (2004). Comorbidity of anxiety disorders with anorexia and bulimia nervosa. *American Journal of Psychiatry*, *161*(12), 2215–2221. https://doi.org/10.1176/appi.ajp.161.12.2215

Kaye, W. H., Fudge, J. L., & Paulus, M. (2009). New insights into symptoms and neurocircuit function of anorexia nervosa. *Nature Reviews Neuroscience*, *10*(8), 573. https://doi.org/10.1038/nrn2682

Kaye, W. H., Wierenga, C. E., Bailer, U. F., Simmons, A. N., & Bischoff-Grethe, A. (2013). Nothing tastes as good as skinny feels: The neurobiology of anorexia nervosa. *Trends in Neurosciences*, *36*(2), 110–120. https://doi.org/10.1016/j.tins.2013.01.003

Keating, C., Tilbrook, A. J., Rossell, S. L., Enticott, P. G., & Fitzgerald, P. B. (2012). Reward processing in anorexia nervosa. *Neuropsychologia*, *50*(5), 567–575. https://doi.org/10.1016/j.neuropsychologia.2012.01.036

Keller, K. L., Steinmann, L., Nurse, R. J., & Tepper, B. J. (2002). Genetic taste sensitivity to 6-n-propylthiouracil influences food preference and reported intake in preschool children. *Appetite*, *38*(1), 3–12. https://doi.org/10.1006/appe.2001.0441

Khalsa, S. S., Craske, M. G., Li, W., Vangala, S., Strober, M., & Feusner, J. D. (2015). Altered interoceptive awareness in anorexia nervosa: Effects of meal anticipation, consumption and bodily arousal. *International Journal of Eating Disorders*, *48*(7), 889–897.

Khalsa, S. S., & Lapidus, R. C. (2016). Can interoception improve the pragmatic search for biomarkers in psychiatry? *Frontiers in Psychiatry*, *7*, ArtID 121,7.

Klein, D. A., Schebendach, J. E., Gershkovich, M., Smith, G. P., & Walsh, B. T. (2010). Modified sham feeding of sweet solutions in women with anorexia nervosa. *Physiology Behaviour*, *101*(1), 132–140. https://doi.org/10.1016/j.physbeh.2010.04.030

Lacey, J. H., Stanley, P. A., Crutchfield, M., & Crisp, A. H. (1977). Sucrose sensitivity in anorexia-nervosa. *Journal of Psychosomatic Research*, *21*(1), 17–21. https://doi.org/10.1016/0022-3999(77)90021-6

Lang, K., Stahl, D., Espie, J., Treasure, J., & Tchanturia, K. (2014). Set shifting in children and adolescents with anorexia nervosa: An exploratory systematic review and meta-analysis. *International Journal of Eating Disorders*, *47*(4), 394–399. https://doi.org/10.1002/eat.22235

Mattes, R. D. (1985). Gustation as a determinant of ingestion: Methodological issues. *American Journal of Clinical Nutrition*, *41*(4), 672–683.

Mattes, R. D. (2011). Accumulating evidence supports a taste component for free fatty acids in humans. *Physiology Behaviour*, *104*(4), 624–631. https://doi.org/10.1016/j.physbeh.2011.05.002

McCrickerd, K., & Forde, C. G. (2016). Sensory influences on food intake control: Moving beyond palatability. *Obesity Reviews*, *17*(1), 18–29. https://doi.org/10.1111/obr.12340

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Plos Medicine*, *6*(7), e1000097. https://doi.org/10.1371/journal.pmed.1000097

Monteleone, A. M., Monteleone, P., Esposito, F., Prinster, A., Volpe, U., Cantone, E., … Maj, M. (2017). Altered processing of rewarding and aversive basic taste stimuli in symptomatic women with anorexia nervosa and bulimia nervosa: An fMRI study. *Journal of Psychiatric Research*, *90*, 94–101. https://doi.org/10.1016/j.jpsychires.2017.02.013

Mueller, C., Kallert, S., Renner, B., Stiassny, K., Temmel, A. F. P., Hummel, T., & Kobal, G. (2003). Quantitative assessment of gustatory function in a clinical context using impregnated "taste strips. *Rhinology*, *41*(1), 2–6.

Najafizade, N., Hemati, S., Gookizade, A., Berjis, N., Hashemi, M., Vejdani, S., … Attab, N. (2013). Preventive effects of zinc sulfate on taste alterations in patients under irradiation for head and neck cancers: A randomized placebo-controlled trial. *Journal of Research in Medical Sciences*, *18*(2), 123–126.

Nakai, Y., Kinoshita, F., Koh, T., Tsujii, S., & Tsukada, T. (1987). Taste function in patients with anorexia-nervosa and bulimia-nervosa. *International Journal of Eating Disorders*, *6*(2), 257–265. https://doi.org/10.1002/1098-108x(198703)6:2<257::aid-eat2260060209>3.0.co;2-x

Nozoe, S. I., Masuda, A., Naruo, T., Soejima, Y., Nagai, N., & Tanaka, H. (1996). Changes in taste responsiveness in patients with anorexia nervosa during behavior therapy. *Physiology Behavior*, *59*(3), 549–553. https://doi.org/10.1016/0031-9384(95)02105-1

Ortega, F. J., Agüera, Z., Sabater, M., Moreno-Navarrete, J. M., Alonso-Ledesma, I., Xifra, G., … Fernández-Real, J. M. (2016). Genetic variations of the bitter taste receptor TAS2R38 are associated with obesity and impact on single immune traits. *Molecular Nutrition & Food Research*, *60*(7), 1673–1683. https://doi.org/10.1002/mnfr.201500804

Overberg, J., Hummel, T., Krude, H., & Wiegand, S. (2012). Differences in taste sensitivity between obese and non-obese children and adolescents. *Archives of Disease in Childhood*, *97*(12), 1048–1052. https://doi.org/10.1136/archdischild-2011-301189

Paulus, M. P., & Stein, M. B. (2010). Interoception in anxiety and depression. *Brain Structure & Function*, *214*(5–6), 451–463. https://doi.org/10.1007/s00429-010-0258-9

Rodin, J., Bartoshuk, L., Peterson, C., & Schank, D. (1990). Bulimia and taste--Possible interactions. *Journal of Abnormal Psychology*, *99*(1), 32–39. https://doi.org/10.1037/0021-843x.99.1.32

Rolls, E. T. (2015). Taste, olfactory, and food reward value processing in the brain. *Progress in Neurobiology*, *127–128*(Supplement C), 64–90. https://doi.org/10.1016/j.pneurobio.2015.03.002

Schebendach, J. E., Klein, D. A., Mayer, L. E. S., Devlin, M. J., Attia, E., & Walsh, B. T. (2014). Assessment of fat taste in individuals with and without anorexia nervosa. *International Journal of Eating Disorders*, *47*(2), 215–218. https://doi.org/10.1002/eat.22226

Schiffman, S. S., & Graham, B. G. (2000). Taste and smell perception affect appetite and immunity in the elderly. *European Journal of Clinical Nutrition*, *54*(S3), S54–S63.

Simon, Y., Bellisle, F., Monneuse, M.-O., Samuel-Lajeunesse, B., & Drewnowski, A. (1993). Taste responsiveness in anorexia-nervosa. *British Journal of Psychiatry*, *162*(02), 244–246. https://doi.org/10.1192/bjp.162.2.244

Steiner, J. E., Glaser, D., Hawilo, M. E., & Berridge, K. C. (2001). Comparative expression of hedonic impact: Affective reactions to taste by human

infants and other primates. *Neuroscience & Biobehavioral Reviews*, *25*(1), 53–74. https://doi.org/10.1016/S0149-7634(00)00051-8

Sunday, S. R., & Halmi, K. A. (1990). Taste perceptions and hedonics in eating disorders. *Physiology Behaviour*, *48*(5), 587–594. https://doi.org/10.1016/0031-9384(90)90196-b

Szalay, C., Ábrahám, I., Papp, S., Takács, G., Lukáts, B., Gáti, Á., & Karádi, Z. (2010). Taste reactivity deficit in anorexia nervosa. *Psychiatry & Clinical Neurosciences*, *64*(4), 403–407. https://doi.org/10.1111/j.1440-1819.2010.02106.x

Tchanturia, K., Davies, H., Roberts, M., Harrison, A., Nakazato, M., Schmidt, U., … Morris, R. (2012). Poor cognitive flexibility in eating disorders: Examining the evidence using the Wisconsin Card Sorting Task. *Plos One*, *7*(1), e28331. https://doi.org/10.1371/journal.pone.0028331

Tepper, B. J., Banni, S., Melis, M., Crnjar, R., & Tomassini Barbarossa, I. (2014). Genetic sensitivity to the bitter taste of 6-n-propylthiouracil (PROP) and its association with physiological mechanisms controlling body mass index (BMI). *Nutrients*, *6*(9), 3363–3381. https://doi.org/10.3390/nu6093363

Toth, E., Tury, F., Gati, A., Weisz, J., Kondakor, I., & Molnar, M. (2004). Effects of sweet and bitter gustatory stimuli in anorexia nervosa on EEG frequency spectra. *International Journal of Psychophysiology*, *52*(3), 285–290. https://doi.org/10.1016/j.ijpsycho.2003.11.001

van Dongen, M. V., van den Berg, M. C., Vink, N., Kok, F. J., & de Graaf, C. (2012). Taste–nutrient relationships in commonly consumed foods. *British Journal of Nutrition*, *108*(01), 140–147. https://doi.org/10.1017/S0007114511005277

Wagner, A., Aizenstein, H., Mazurkewicz, L., Fudge, J., Frank, G. K., Putnam, K., … Kaye, W. H. (2008). Altered insula response to taste stimuli in individuals recovered from restricting-type anorexia nervosa. *Neuropsychopharmacology*, *33*(3), 513–523. https://doi.org/10.1038/sj.npp.1301443

Westwood, H., Stahl, D., Mandy, W., & Tchanturia, K. (2016). The set-shifting profiles of anorexia nervosa and autism spectrum disorder using the Wisconsin Card Sorting Test: A systematic review and meta-analysis. *Psychological Medicine*, 1809–1827. https://doi.org/10.1017/S0033291716000581

Wockel, L., Hummel, T., Zepf, F. D., Jacob, A., & Poustka, F. (2007). [Changed taste perception in patients with eating disorders]. *Zeitschrift für Kinder-& Jugendpsychiatrie & Psychotherapie*, *35*(6), 423–434. https://doi.org/10.1024/1422-4917.35.6.423

Wockel, L., Jacob, A., Holtmann, M., & Poustka, F. (2008). Reduced number of taste papillae in patients with eating disorders. *Journal of Neural Transmission*, *115*(3), 537–544. https://doi.org/10.1007/s00702-007-0845-y

Yoshida, R., Shin, M., Yasumatsu, K., Takai, S., Inoue, M., Shigemura, N., … Ninomiya, Y. (2017). The role of cholecystokinin in peripheral taste signaling in mice. *Frontiers in Physiology*, *8*(866). https://doi.org/10.3389/fphys.2017.00866

How to cite this article: Kinnaird E, Stewart C, Tchanturia K. Taste sensitivity in anorexia nervosa: A systematic review. *Int J Eat Disord*. 2018;00:1–14. https://doi.org/10.1002/eat.22886

Chapter 11: The relationship of autistic traits to taste and olfactory processing in anorexia nervosa

Kinnaird, E., Stewart, C. & Tchanturia, K. (2020). The relationship of autistic traits to taste and olfactory processing in anorexia nervosa. *Molecular Autism, 11*(25). doi:10.1186/s13229-020-00331-8

Kinnaird et al. Molecular Autism (2020) 11:25
https://doi.org/10.1186/s13229-020-00331-8

Molecular Autism

RESEARCH Open Access

The relationship of autistic traits to taste and olfactory processing in anorexia nervosa

Emma Kinnaird[1], Catherine Stewart[2] and Kate Tchanturia[1,3,4*]

Abstract

Background: There is a heightened prevalence of autism in anorexia nervosa (AN) compared to the general population. Autistic people with AN experience a longer illness duration and poorer treatment outcomes. Whether sensory differences in autism could contribute to altered taste and smell as a potential maintaining factor in AN is under-explored. The aim of this study was to explore whether autistic traits are associated with taste and olfaction differences in AN.

Methods: The study recruited $n = 40$ people with AN, and $n = 40$ healthy controls (HC). Smell sensitivity was measured using the Sniffin' Sticks test. Taste sensitivity was measured using taste strips. Participants self-rated their autistic traits using the Autism Spectrum Quotient.

Results: There were no significant differences on taste and olfactory outcomes between people with AN and HC. These findings did not change after controlling for the heightened levels of autistic traits in the AN group. No relationship between taste and smell outcomes and autistic traits were identified within the AN group.

Limitations: The current study is not able to draw conclusions about taste and smell processing in co-occurring autism and AN as it only measured levels of autistic traits, rather than comparing people with and without an autism diagnosis.

Conclusions: No significant associations between autistic traits and taste and smell processing in AN were identified. Future research should consider further exploring this area, including by comparing autistic women to women with AN.

Keywords: Anorexia nervosa, Eating disorders, Autism, Sensory, Taste, Olfaction

Background

Anorexia nervosa (AN) is an eating disorder (ED) characterised by the core symptoms of persistent food restriction, associated low body weight, resistance to weight gain, and body image disturbances [1]. Autistic traits are known to be heightened in AN, with around 20-25% of individuals presenting with clinically significant levels of autistic characteristics on clinical measures [2, 3]. When these measures of current autistic traits are combined with developmental assessments, around 10% of people with AN meet the diagnostic criteria for autism [4]. Significantly, autistic people with AN may experience a longer illness duration, and poorer treatment outcomes in the absence of appropriate adaptations [5–7].

Consequently, there is an increasing interest in exploring characteristics associated with autism that may play a role in maintenance models of AN, contributing to

* Correspondence: kate.tchanturia@kcl.ac.uk
[1]Department of Psychological Medicine, Institute of Psychology, Psychiatry and Neuroscience, King's College London, London, UK
[3]Eating Disorders Service, South London and Maudsley NHS Foundation Trust, London, UK
Full list of author information is available at the end of the article

these poorer outcomes. For example, previous studies have investigated similarities in cognitive rigidity and theory of mind difficulties in AN and autism, both of which are thought to act as potential perpetuating factors in the illness [8–10]. To date, there is less research on the implications of sensory sensitivity in autism for AN. Sensory differences driven by alterations in bottom-up processing are common in autism, to the extent that atypical responses to sensory stimuli have been included as a diagnostic criteria in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [1, 11]. Qualitative research on co-occurring autism and AN has highlighted sensory sensitivities as potentially contributing to eating difficulties in AN; however, this area remains under-explored using experimental methods [12, 13]. This is significant as sensory sensitivity may play a role in neurobiological models of AN maintenance. Brain imaging research suggests that food restriction in this condition may be maintained by alterations in neural networks informing appetite regulation, including in areas related to taste and smell processing [14, 15]. Specifically, a number of these studies have detected alterations in the anterior insula in response to taste stimuli [16–18]. The anterior insula is crucial to flavour perception as it integrates taste and olfactory peripheral inputs, although to date no brain imaging studies in AN have examined this area in response to olfactory stimuli [19].

Therefore, alterations in taste and smell sensitivity could potentially contribute to the dysregulation of this neural network, contributing to the key AN symptom of food restriction. Significantly, both taste and olfaction are thought to be altered in autism. Autistic people have a lowered ability to identify tastes, but appear to have normal detection thresholds [20–22]. Systematic reviews suggest that research on olfaction is more mixed [23, 24]. A recent meta-analysis on odour identification and detection thresholds found large heterogeneity in autism, with evidence for both lowered and heightened sensitivity [25].

Whether taste and olfaction are altered in AN remains unclear. As well as responding to the taste and olfactory qualities of food, the anterior insula also appears to be involved in reward and affective assessments [26, 27]. Therefore, from brain imaging evidence only it is difficult to isolate whether alterations in this area suggest altered bottom-up processing of sensory stimuli in AN, or reflect alterations in top-down processing in hedonic and reward related regions [28–30]. Recent systematic reviews on taste and smell in AN highlighted that findings in this area are mixed and inconsistent, ranging from heightened sensitivity, lowered sensitivity, or no significant findings [31, 32]. In the context of these mixed findings, it is possible that taste and smell sensitivity are not consistently altered in AN. Rather, altered sensitivity may be related to specific states associated with AN, rather than representing a core trait of the illness itself. For example, comorbid diagnoses of mood disorders or anxiety are common in this population, and both depression and anxiety are known to be associated with altered taste and olfaction [33–36].

However, to date the potential significance of co-occurring autism in taste and smell sensitivity in AN remains under-explored. To date, two studies on smell sensitivity only have included measures of autistic traits in their analyses with conflicting results; in Bentz et al. (2017), including measures of social and communication differences associated with autism as a covariate in the analysis did not alter their findings of heightend smell sensitivity, and there was no relationship between these differences and sensory outcomes [37]. By contrast, Tonacci et al. (2019) found that adolescents with AN did not differ from healthy controls (HC) on smell sensitivity, but did find a correlation between smell sensitivity and parent-reported autistic traits [38].

Therefore, the aims of this study were to explore whether people with AN experience taste and smell differences compared to HC, and whether taste and smell in AN is associated with autistic traits. In the context of previous mixed findings in the area of sensory sensitivity in AN, this study did not generate specific hypotheses prior to data collection.

Methods

Participants

In total, 40 people with AN and 40 HC were recruited into the study. All participants were aged 18-55. Exclusion criteria for all participants included any current medical condition that might affect their taste or smell capacity (for example, neurological disorders such as epilepsy or Parkinson's disease). Participants experiencing a short-term condition (such as a cold or hay fever) had their testing delayed until after they had recovered.

Participants with AN were recruited from South London and Maudsley NHS Foundation Trust (SLAM) ED service. Additional participants were recruited by advertising online with a UK-based ED charity. Inclusion criteria for people with AN were a diagnosis of AN, confirmed using the Structured Clinical Interview for DSM (SCID-5) [39]. The SCID-5 was additionally used to evaluate whether the participant was experiencing restrictive AN (AN-R) or binge/purge AN (AN-BP).

HCs were included through online advertisements, and through the local university. HCs were excluded if they self-reported a diagnosis of autism, or had ever experienced an ED or other mental health condition. The absence of a previous ED or psychiatric disorder was confirmed using the SCID-5 screening tool prior to testing. The absence of a potential autism spectrum

condition was confirmed using the Autism Quotient, with HC only included if they scored below the recommended 32 score threshold [40].

Measures

Demographic and clinical information

Participants were asked to self-report information on their age, ethnicity, psychiatric medication use, and whether they currently or previously smoked. People with AN self-reported their illness duration. Individuals with AN currently in treatment had their body mass index (BMI) taken from their most recent measurements in clinical notes. HC and individuals with AN not in treatment had their height and weight assessed on the day of testing.

Smell sensitivity

The Sniffin' Sticks extended test (purchased from MediSense) was used to measure three domains of smell sensitivity: odour threshold, odour discrimination, and odour identification [41]. This test was chosen as it is a standardised measure that has been used in the majority of previous research on smell sensitivity in AN [31]. The recommended procedure of the test was followed, with the exception that participants were asked to close their eyes rather than using a blindfold. During the testing, participants are asked to smell felt-tip pens filled with odours, which are held 2 cm in front of the centre of both nostrils. Higher scores on each test indicate higher smell sensitivity.

Odour threshold

The threshold test assesses at what threshold participants can detect the smell of *n*-butanol across 16 concentrations. Participants close their eyes, and are then presented with three pens in a forced choice paradigm: one pen contains *n*-butanol, whilst the other two contain a non-smelling solvent. Participants are instructed to identify the pen containing the odour. If the participant identifies the pen correctly twice in a row, they are presented with a set of pens at a lower concentration. If they do not correctly identify the *n*-butanol pen, the test proceeds to a set of pens at a higher concentration. The final score is the mean of the last four turning points (where the participant identifies a pen set correctly after previous incorrect identifications, or where the participant incorrectly identifies a pen set after previous correct identifications).

Odour discrimination

The discrimination test measures the ability to tell the difference between smells. Participants are asked to identify the unique odour pen from a set of 3 pens: each set has 2 pens that smell the same, and one unique pen. This is a forced choice test, and is repeated 16 times with different smell variations. Participants closed their eyes during the test.

Odour identification

The identification test is a multiple-choice test; the researcher presents participants with one odour pen at a time. Participants then identify the smell from a card with four different options. This is repeated 16 times, with 16 different odours.

Taste strips

Taste sensitivity was assessed using taste strips, purchased from MediSense [42]. This test was used as it represents a standardised measure of a method widely used in taste research in AN, whereby taste sensitivity is assessed via the administration of tastes at varying concentrations [32]. Taste strips measure taste identification only. Participants are presented with 16 strips of filter paper, each impregnated with four ascending concentrations of the four basic tastes: sweet, salty, sour and bitter. Participants are asked to place the strip in the centre of their tongue, and to identify whether the strip was sweet, salty, sour, bitter or had no taste. Following each strip, participants rinse their mouth with water. Each correct answer yielded one point, giving a maximum score of 16, and 4 for each individual taste quality. Scores were then summed to give a total score, and scores for each taste quality. Higher scores indicate taste smell sensitivity; lower scores indicate lower taste sensitivity.

Sensory perception quotient

Self-perceived sensitivity to external sensations, such as taste and smell, was measured using the Sensory Perception Quotient (SPQ) [43]. The SPQ was designed to measure sensory perception difficulties associated with autism in adults, and evaluates the five basic exteroceptive sensory modalities (vision, hearing, touch, smell and taste). The participant is presented with 92 different statements on sensory sensitivity, and responds on a four-point Likert scale from 'strongly agree' to 'strongly disagree'. A total of 16 items measure taste, and 16 items measure smell. In contrast to the experimental measures of taste and smell, a higher score indicates lower sensitivity, and a lower score indicates higher sensitivity. This is the first use of the SPQ in people with AN.

Autism quotient

Participants completed the adult Autism Spectrum Quotient (AQ), a self-report measure designed to screen adults for the presence of autistic traits [40]. Participants respond to 50 statements reflecting autistic traits on a four-point Likert scale from 'definitely agree' to 'definitely disagree'. A higher score indicates higher levels of

autistic traits, with a score of ≥ 32 indicating potentially clinically significant levels of autistic traits. The AQ was used in this current study to screen HC for clinically significant levels of autistic traits as it has shown to have good validity distinguishing cases from controls. However, recent studies suggest it may be less effective in predicting an autism diagnosis in clinical populations with high levels of suspected autistic traits [44–46]. In light of this research, the AQ was not used to categorise people with AN in this study as above or below threshold on the AQ, but rather was used as a continuous measure of autistic traits. The AQ has been previously used in AN populations, with people with AN typically scoring higher compared to HC [47].

Eating disorder examination questionnaire

ED symptoms were measured using the Eating Disorder Examination questionnaire (EDE-Q) [48]. The EDE-Q is a standardised and well validated self-report measure of the severity of the characteristic psychopathology of ED. It contains 36 items which ask respondents to rate how often they have engaged in certain eating disordered behaviours or held disordered concerns over the past 28 days. The scores result in a 'global' score that represents the mean of the four subscale scores: 'eating concern', 'weight concern', 'shape concern' and 'restriction'. Higher scores indicate higher levels of ED symptoms.

Hospital anxiety and depression scale

The presence of anxiety or depression was assessed using the Hospital Anxiety and Depression Scale (HADS) [49]. The HADS is a widely used 14-item self-rating instrument for anxiety and depression in patients with both physical and mental health problems. The maximum possible score on either subscale (anxiety/depression) is 21, with higher scores indicating higher symptom levels.

Procedure

All testing took place during one session. Following informed consent, demographic and clinical information was collected from participants. Participants then completed measures in the following order: the self-report questionnaires, the smell tests and finally the taste tests. Participants were given the option to complete the self-report questionnaires before or after the session if preferable. One participant with AN declined to complete the taste test, but participated in the smell test. A small number of participants completed the taste and smell tests, but did not fully complete all self-report questionnaires. Their data has been included in the analysis. Where group sizes vary across measures, this has been highlighted in the result tables.

Statistical analysis

Data distribution was assessed using Shapiro-Wilk tests and visual checking of histograms. The following variables were found to have a non-normal distribution and so were transformed: age, odour discrimination, and odour identification. However, the following variables could not be transformed and so were analysed using non-parametric tests: BMI, EDE-Q global scores, HADS depression scores, the vision domain of the SPQ and all taste outcomes excepting sour.

Group differences on each variable were initially explored using *t* tests, with Mann-Whitney *U* tests used for non-normal distributions. Effect sizes were calculated using Cohen's *d*. Categorical variables were compared using Fisher's exact test. As the analysis involved multiple comparisons, the study used the Bonferroni correction to calculate a more conservative significance value of $p = 0.005$.

Analyses of taste and smell outcomes were then repeated to control for potential confounding variables. Firstly, comparisons were rerun to exclude people who had ever smoked from each group (removing $n = 10$ HC, and $n = 10$ people with AN). Secondly, to control for the potential role of medication use on sensory outcomes, the AN group was split into two sub-groups: (1) those taking psychiatric medication ($n = 25$) and (2) those not taking psychiatric medication ($n = 15$). These sub-groups were then compared on each measure.

After checking for model assumptions, ANCOVAs were performed on the smell outcomes to control for the independent contributions of anxiety and autistic traits in comparisons of sensory variables. An ANCOVA could not be performed on taste outcomes or to control for depression due to data not meeting model assumptions. To explore relationships between sensory outcomes and autistic traits, a multiple regression analysis was run within the AN group only to explore the role of autistic traits whilst controlling for the relative contributions of anxiety and depression. Finally, a Spearman's rank correlation analysis was performed to assess whether there was any association between age and sensory outcomes.

Results

Participant characteristics

Both groups were matched on age, gender, and whether they had ever smoked. Within the AN group, mean illness duration was 9.76 years ($SD = 8.00$). Thirty-four participants (85.00%) reported experiencing AN-R, compared to 6 participants (15.00%) with AN-BP. Eight (20.00%) of participants were in inpatient treatment at the time of the study, 23 (57.50%) participants were attending outpatient treatment, and 9 (22.50%) participants were not in treatment. Twenty-six participants with AN (65.00%) self-reported a diagnosis of at least one comorbid psychiatric condition, including anxiety,

depression, obsessive compulsive disorder or borderline personality disorder.

Demographic and clinical characteristics for each group are summarised in Table 1. People with AN had significantly lower BMIs compared to the HC group, and significantly higher levels of ED symptomatology, autistic traits, anxiety and depression.

Self-rated sensory sensitivity (SPQ)

N = 38 HC, and n = 40 people with AN, completed the SPQ (Fig. 1). People with AN scored significantly lower on touch sensitivity (t (76) = 2.90, p = 0.005, d = 0.66). Lower scores on the SPQ indicate higher self-rated sensitivity, suggesting that people with AN considered themselves to be significantly more sensitive to touch compared to HC. There were no significant differences between AN and HC groups in any other domains.

Smell and taste sensitivity

Group differences on objective measures of smell and taste sensitivity are summarised in Table 2. There were no significant differences between groups on any outcome measure.

Excluding participants from both groups who ever smoked from the analysis did not change the direction of the results. There were no significant differences on any outcome between participants with AN not taking psychiatric medication, and those currently taking psychiatric medication. Adjusting group comparisons for the heightened levels of anxiety and autistic traits in the AN group using separate ANCOVAs did not alter the results. Result tables for these secondary analyses are located in Additional file 1.

Relationships between clinical variables

Regression analyses were performed within the AN group to explore the relative contributions of anxiety, depression and autistic traits to sensory measures. With the significance level set at p = 0.005, these variables were not found to individually contribute to any sensory outcome at a significant level (Table 3).

A correlation analysis was also performed to explore whether there was an association between age and sensory outcomes. No significant correlations were found (Table 4).

Discussion

The aims of this study were to explore whether people with AN experience taste and smell differences compared to HC, and whether taste and smell in AN is associated with autistic traits. The analyses identified no significant differences on taste and smell outcomes between people with AN and HC, and no significant associations between taste, smell and autistic traits within the AN group.

Overall, people with AN did not exhibit significant differences on objective measures of sensory sensitivity compared to HC, including after controlling for the potential role of autistic traits. If the absence of significant differences identified in the analysis reflects a true absence of difference, this could suggest that identified alterations in appetite neurocircuitry in AN are driven by differences in top-down processing relating to perceived reward, hedonic and affective salience, rather than bottom-up differences at a sensory level [16–18]. By contrast, previous research in autism has found lowered taste sensitivity [20, 21]. Findings on smell sensitivity in autism are comparably less consistent, with evidence for both heightened and lowered olfaction [25, 50]. If AN and autism are associated with different processes relating to taste, and potentially smell, this could explain why autistic traits were not found to be related to sensory sensitivity in AN in our study.

However, the current study cannot draw conclusions surrounding whether AN and autism are associated with

Table 1 Group demographic and clinical characteristics

	HC mean (SD) (n = 40)	AN mean (SD) (n = 40)	Test statistic	p	Effect size (d (95% CI))
Age (years)	26.45 (7.55)	26.65 (8.60)	t(78) = − 0.33	0.741	− 0.07 (− 0.51-0.36)
Gender	n = 38 female (95.00%) n = 2 male (5.00%)	n = 38 female (95.00%) n = 2 male (5.00%)		1.00	
BMI*	22.5 (4.3)	15.75 (1.22)	U = 0	≤ 0.001	2.92 (2.27-3.55)
Smoking (% never smoked)	n = 30 (75.00%)	n = 30 (75.00%)		1.00	
Psychiatric medication (% currently taking)	n = 0 (0.00%)	n = 25 (62.50%)		≤ 0.001	
EDE-Q global*	0.58 (0.9) n = 39	4.05 (1.79) n = 39	U = 74	≤ 0.001	− 2.90 (− 3.54-2.26).
AQ	12.48 (6.74)	23.55 (10.26)	t (78) = − 5.71	≤ 0.001	− 1.28 (− 1.75-0.79)
HADS depression*	2 (4) n = 39	9 (5) n = 39)	U = 174.5	≤ 0.001	− 1.79 (− 2.32-1.26).
HADS anxiety	6.08 (3.80) n = 39	13.00 (4.63) n = 39	t (76) = − 7.21	≤ 0.001	− 1.63 (− 2.14-1.12)

*Indicates non-normally distributed data. Medians and interquartile ranges presented instead of means/standard deviations (SD). Effect sizes presented with 95% confidence intervals (CI)

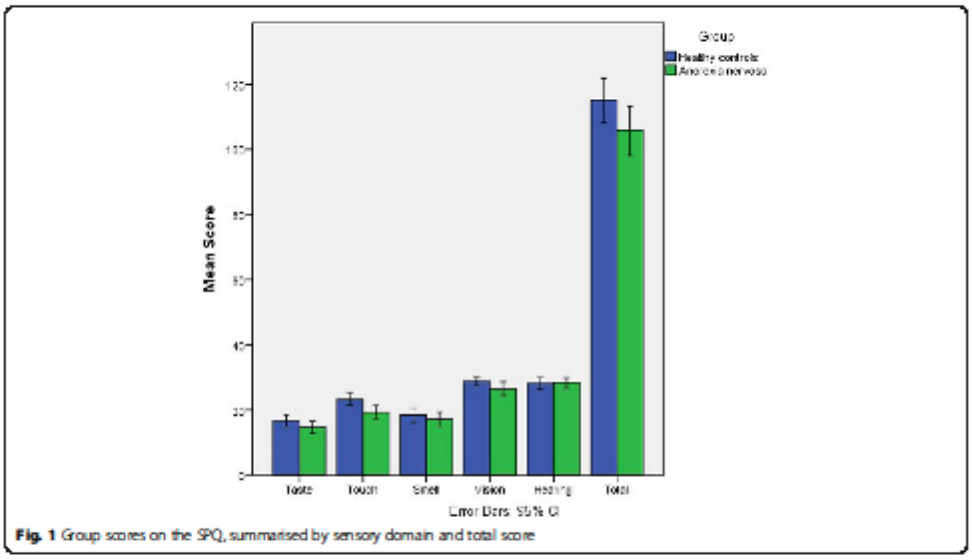


Fig. 1 Group scores on the SPQ, summarised by sensory domain and total score

different sensory processing as an autism comparison group was not included. Moreover, previous research on smell and taste processing in autism may lack comparability to studies in AN, including the present paper. The current study, and most previous research on taste and smell sensitivity in AN, has used a predominantly female adult sample [31, 32]. By contrast, research in this area in autism has used predominantly male samples, with a greater focus on children [23–25, 50]. Both age and gender are known to affect sensory processing, particularly in the area of olfaction. Research suggests that olfactory performance improves throughout childhood, reaching adult levels in the later teenage period [51]. Both taste and smell performance then declines after the sixth decade of life [52, 53]. Women also appear to outperform men on smell tests, and there is some evidence that women process tastes differently in the brain [54, 55]. In this context, it is difficult to draw firm conclusions comparing research from these different fields due to the difference in samples. Future research should consider comparing taste and smell processing in autistic people to people with AN, with age and gender-matched samples, to further explore this area.

Previous research on whether there is a relationship between smell sensitivity and autistic traits in AN has yielded mixed results (to date, no study has examined taste sensitivity). One study found a relationship between parent-reported autistic traits and olfaction [38],

Table 2 Taste and smell group outcomes

	HC mean (*SD*) (*n* = 40)	AN mean (*SD*) (*n* = 40)	Test statistic	*p*	Effect size (*d* (95% CI))
Smell total	36.28 (4.07)	35.7 (4.36)	$t(78) = 0.62$	0.539	0.14 (0.30-0.58)
Odour threshold	9.88 (3.09)	10.80 (2.84)	$t(78) = -1.38$	0.170	−0.31 (−0.75-0.13)
Odour discrimination	12.98 (1.69)	12.15 (2.35)	$t(78) = 1.72$	0.089	0.39 (−0.06-0.83)
Odour identification	13.43 (1.85)	12.75 (1.69)	$t(78) = 1.99$	0.050	0.45 (0.00-0.89)
	HC mean (*SD*) (*n* = 40)	AN mean (*SD*) (*n* = 39)			
Taste total*	13 (4)	11 (5)	$U = 628.5$	0.135	0.36 (−0.09-0.80)
Sweet*	4 (1)	4 (1)	$U = 719$	0.502	0.17 (−0.27-0.61)
Sour	2.40 (1.08)	1.82 (1.30)	$t(77) = 2.16$	0.034	0.49 (0.04-0.93).
Salty*	4 (1)	4 (1)	$U = 742.5$	0.686	0.11 (−0.34-0.55)
Bitter*	3 (2)	3 (2)	$U = 692.5$	0.369	0.21 (−0.23-0.65)

*Indicates non-normally distributed data. Medians and interquartile ranges presented instead of means/standard deviations (*SD*)

Table 3 Regression analysis of relative contribution of anxiety, depression and autistic traits to sensory outcomes

	Anxiety (HADS)			Depression (HADS)			Autistic traits (AQ)		
	B	*t*	*p*	*B*	*t*	*p*	*B*	*t*	*p*
Smell total	0.24	1.35	0.186	− 0.07	− 0.39	0.702	− 0.02	− 0.11	0.913
Odour threshold	0.01	0.03	0.975	0.16	0.83	0.414	0.05	0.29	0.772
Odour discrimination	0.37	2.13	0.040	− 0.06	− 0.34	0.738	− 0.15	− 0.84	0.407
Odour identification	0.10	0.57	0.570	− 0.38	− 2.10	0.043	0.07	0.38	0.706
Taste total	0.15	0.83	0.411	− 0.19	− 0.99	0.329	− 0.02	− 0.12	0.906
Sweet	0.07	0.40	0.691	− 0.19	− 0.98	0.333	0.02	0.10	0.925
Sour	0.32	1.83	0.076	− 0.27	− 1.49	0.145	0.06	0.35	0.726
Salty	0.17	0.94	0.354	− 0.14	− 0.76	0.452	− 0.05	− 0.26	0.795
Bitter	− 0.11	− 0.58	0.563	0.04	0.20	0.844	− 0.08	− 0.43	0.669

and another found no relationship between social and communicative characteristics of autism and smell outcomes [37]. It should be noted that autistic traits have not consistently found to be related to smell sensitivity even in autistic populations, with studies finding conflicting results [50, 56, 57]. One possibility for these mixed findings is that the heightened levels of autistic traits influence smell outcomes via a secondary, mediating variable. For example, anxiety and sensory sensitivity are known to be interrelated features in autism [58]. A strength of the present study is that the relationship of autistic traits and sensory outcomes in AN was analysed relative to the contributions of anxiety and depression using a multiple regression analysis. This is important as both anxiety and depression are known to influence taste and smell processing, including in AN [33, 34, 37]. The lifetime prevalence rate of anxiety in autistic adults is 42%, and 37% for depression [59]. Additionally, anxiety has been shown to correlate with autistic traits in AN [60]. Therefore, the finding of this study that autistic traits were not significantly related to objective measures of taste and smell sensitivity are likely to be more robust against the influence of these interrelated variables.

Table 4 Correlation analysis between age and sensory outcomes

	Age (years)	
	r	*p*
Smell total	0.22	0.171
Odour threshold	0.06	0.701
Odour discrimination	0.024	0.135
Odour identification	0.34	0.031
Taste total	0.13	0.419
Sweet	− 0.08	0.599
Sour	0.11	0.515
Salty	− 0.02	0.911
Bitter	0.18	0.287

However, the current study did not explore IQ as a potential confounding variable, although it has previously been identified as a moderating factor in smell sensitivity in autism [25]. Additionally, this study did not control for age beyond excluding people aged over 55 years, although no significant relationship between age and sensory outcomes was identified in the current study. Therefore, future research exploring smell sensitivity, autism and anorexia could further consider the potential role of mediating variables in this relationship.

On self-report measures people with AN exhibited no significant differences in taste and smell sensitivity compared to HC. Previous research indicates that people with AN may rate themselves as significantly more sensitive to sensations, and may be more likely to attempt to avoid sensory stimuli compared to HC [61, 62]. As the self-report measures in this study reflect the objective outcomes, it is possible that the SPQ represents an accurate measure of sensory sensitivity only in this population, whereas previous studies additionally measured affective or hedonic responses to sensory stimuli [61, 62]. In the current study, people with AN only rated themselves as more sensitive to touch. The area of touch sensitivity has primarily been explored through the paradigm of affective touch: people with AN perceive affective, interpersonal touching as less pleasurable compared to HC [63]. Future research could consider if the pleasurable aspects of interpersonal touch may also be related to an underlying sensory hypersensitivity to touch itself.

Limitations

A limitation of this study was that it measured self-rated levels of autistic traits in people with AN, rather than comparing autistic people with AN to those with AN only. Therefore, it cannot draw conclusions on whether these two groups do experience differences in taste and smell sensitivity. Further research should consider autistic people to people with AN only, including matching

for age and gender. Future research could also explore using clinical and developmental autism assessments to establish a co-occurring autism/AN group, and compare to people with AN only and HC. An additional limitation of this study is that whilst it used a heterogenous AN sample that may better reflect clinical variety, the sample was not large enough to control within the analysis for potential confounding factors introduced by this heterogeneity. For example, the current study did not explore the potential role of illness duration, BMI or comorbidities beyond anxiety and depression.

Furthermore, although the findings of this study were non-significant, the methods used cannot account for whether this reflects a true absence of difference between groups, or whether these non-significant findings result from chance or a lack of power [64]. However, sample size calculations to determine the minimum sample size required for adequate study power were calculated a priori to recruitment on the basis of two previous studies in AN which measured the same taste and smell outcomes as the present research, and which reported means and standard deviations [65, 66]. These calculations suggested that a minimum sample size approximating $n = 20$ in each group would give sufficient statistical power, although the current study recruited larger groups due to its aim to investigate potential covariates. This indicates that the lack of significant findings is unlikely to be due to a lack of power. Additionally, the finding that confidence intervals for the majority of taste and smell outcomes includes 0 supports an absence of significant difference. However, without a Bayesian approach to analysis the current study cannot precisely quantify the level of evidence for whether there is truly no difference between groups.

Conclusions

The study found that taste and smell sensitivity was not significantly altered in AN, with no significant relationship between these outcomes and autistic traits within the AN group. In the context of previous studies suggesting altered taste and smell sensitivity in autism, future research should explore sensory differences in autistic people compared to people with AN, and implications for individuals with co-occurring autism and AN.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s13229-020-00331-8.

Additional file 1. Secondary Analysis Results. File including results tables for secondary analyses.

Abbreviations

AN: Anorexia nervosa; AN-BP: Anorexia nervosa, binge-purge subtype; AN-R: Anorexia nervosa, restrictive subtype; AQ: Autism Quotient (Adult); BMI: Body mass index; CI: Confidence Intervals; DSM: Diagnostic and Statistical Manual of Mental Disorders; ED: Eating disorder; EDE-Q: Eating Disorder Examination Questionnaire; HADS: Hospital Anxiety and Depression Scale; HC: Healthy control; SCID-S: Structured Clinical Interview for DSM; SD: Standard deviations; SLAM: South London and Maudsley NHS Foundation Trust; SRQ: Sensory Perception Quotient; UK: United Kingdom

Acknowledgements

The authors would like to thank the UK ED charity Beat for their support with study recruitment.

Authors' contributions

All authors contributed to the design of the study. EK collected the data and performed the analysis, with supervision from KT and CS. EK wrote the first draft of the manuscript, with subsequent input from KT and CS. All authors read and approved the final manuscript.

Funding

EK was supported by a Medical Research Council Doctoral Training Partnership studentship (MR/N013700/1). KT would like to acknowledge support from the Health foundation, an independent charity committed to bring better health care for people in the UK (AIMS ID: 1115447). KT would also like to acknowledge two grants from the MRC-MRF fund (MR/S020888/1, BiomaRkers for Anorexia NErvosa and autism spectrum Disorders- longitudinal study; and MR/RD04595/1 The Triple A study (Adolescents with Anorexia and Autism): A search for biomarkers).

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

All participants gave written informed consent prior to participation, and the study received ethnical approval from the North East Newcastle & North Tyneside 2 research ethics committee (18/NE/0193).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]Department of Psychological Medicine, Institute of Psychology, Psychiatry and Neuroscience, King's College London, London, UK. [2]Maudsley Centre for Child and Adolescent Eating Disorders, South London and Maudsley NHS Foundation Trust, London, UK. [3]Eating Disorders Service, South London and Maudsley NHS Foundation Trust, London, UK. [4]Department of Psychology, Illia State University, Tbilisi, Georgia.

Received: 29 November 2019 **Accepted:** 27 March 2020
Published online: 16 April 2020

References

1. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. 5 ed. Arlington, VA: American Psychiatric Publishing; 2013.
2. Westwood H, Mandy W, Tchanturia K. Clinical evaluation of autistic symptoms in women with anorexia nervosa. Molecular Autism. 2017;8.
3. Bentz M, Jepsen JR, Pedersen T, Bulik CM, Pedersen L, Pagsberg AK, et al. Impairment of social function in young females with recent-onset anorexia nervosa and recovered individuals. The Journal of adolescent health : official publication of the Society for Adolescent Medicine. 2017;60(1):23–32.
4. Westwood H, Mandy W, Simic M, Tchanturia K. Assessing ASD in adolescent females with anorexia nervosa using clinical and developmental measures: a preliminary investigation. J Abnormal Child Psychol. 2017.
5. Tchanturia K, Larsson E, Adamson J. How anorexia nervosa patients with high and low autistic traits respond to group cognitive remediation therapy. BMC Psychiatry. 2016;16.
6. Nielsen S, Anckarsater H, Gillberg C, Rastam M, Wentz E. Effects of autism spectrum disorders on outcome in teenage-onset anorexia nervosa

evaluated by the Morgan-Russell outcome assessment schedule: a controlled community-based study. Molecular Autism. 2015;6.
7. Stewart CS, McEwen FS, Konstantellou A, Eisler I, Simic M. Impact of ASD Traits on treatment outcomes of eating disorders in girls. European Eating Disorders Review. 2017;25(2):123–8.
8. Westwood H, Stahl D, Mandy W, Tchanturia K. The set-shifting profiles of anorexia nervosa and autism spectrum disorder using the Wisconsin Card Sorting Test: a systematic review and meta-analysis. Psychological Medicine. 2016;46(9):1809–27.
9. Treasure J, Schmidt U. The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. Journal of Eating Disorders2013.
10. Leppanen J, Sedgewick F, Treasure J, Tchanturia K. Differences in the theory of mind profiles of patients with anorexia nervosa and individuals on the autism spectrum: a meta-analytic review. Neurosci Biobehav Rev. 2018;90:146–63.
11. Robertson CE, Baron-Cohen S. Sensory perception in autism. Nat Rev Neurosci. 2017;18(11):671–84.
12. Kinnaird E, Norton C, Tchanturia K. Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study. BMC Psychiatry. 2017;17:292.
13. Kinnaird E, Norton C, Stewart C, Tchanturia K. Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment? Int Rev Psychiatry. 2019;31(4):308–17.
14. Kaye WH. Eating disorders: hope despite mortal risk. Am J Psychiatry. 2009;166(12):1309–11.
15. Kaye WH, Wierenga CE, Bailer UF, Simmons AN, Bischoff-Grethe A. Nothing tastes as good as skinny feels: the neurobiology of anorexia nervosa. Trends Neurosci. 2013;36(2):110–20.
16. Oberndorfer TA, Frank GKW, Simmons AN, Wagner A, McCurdy D, Fudge JL, et al. Altered insula response to sweet taste processing after recovery from anorexia and bulimia nervosa. Am J Psychiatry. 2013;170(10):1143–51.
17. Frank GK, Shott ME, Hagman JO, Mittal VA. Alterations in brain structures related to taste reward circuitry in ill and recovered anorexia nervosa and in bulimia nervosa. Am J Psychiatry. 2013;170(10):1152–60.
18. Frank GK, Shott ME, Keffler C, Comier M-A. Extremes of eating are associated with reduced neural taste discrimination. International Journal of Eating Disorders. 2016;49(6):603–12.
19. Small DM. Flavor is in the brain. Physiology & behavior. 2012;107(4):540–52.
20. Tavassoli T, Baron-Cohen S. Taste identification in adults with autism spectrum conditions. Journal of Autism and Developmental Disorders. 2012;42(7):1419–24.
21. Bennetto L, Kuschner ES, Hyman SL. Olfaction and taste processing in autism. Biological psychiatry. 2007;62(9):1015–21.
22. Damiano CR, Aloi J, Burrus C, Garbutt JC, Kampov-Polevoy AB, Dichter GS. Intact hedonic responses to sweet tastes in autism spectrum disorder. Research in autism spectrum disorders. 2014;8(3):230–6.
23. Tonacci A, Billeci L, Tartarisco G, Ruta L, Muratori F, Pioggia G, et al. Olfaction in autism spectrum disorders: a systematic review. Child Neuropsychology. 2017;23(1):1–25.
24. Boudjarane MA, Grandgeorge M, Martanowski R, Mikary L, Lemonnier E. Perception of odors and tastes in autism spectrum disorders: a systematic review of assessments. Autism Research. 2017;10(6):1045–57.
25. Larsson M, Tirado C, Wiens S. A meta-analysis of odor thresholds and odor identification in autism spectrum disorders. Front Psychol. 2017;8679.
26. Small DM, Zatorre RJ, Dagher A, Evans AC, Jones-Gotman M. Changes in brain activity related to eating chocolate: from pleasure to aversion. Brain. 2001;124(9):1720–33.
27. Craig AD. How do you feel - now? The anterior insula and human awareness. Nature Reviews Neuroscience. 2009;10(1):59–70.
28. Brooks S-J, Barker GJ, O'Daly OG, Brammer M, Williams SCR, Benedict C, et al. Restraint of appetite and reduced regional brain volumes in anorexia nervosa: a voxel-based morphometric study. Bmc Psychiatry. 2011;11.
29. Titova OE, Hjorth OC, Schiöth HB, Brooks SJ. Anorexia nervosa is linked to reduced brain structure in reward and somatosensory regions: a meta-analysis of VBM studies. BMC Psychiatry. 2013;13(1):110.
30. Keating C, Tilbrook AJ, Rossell SL, Enticott PG, Fitzgerald PB. Reward processing in anorexia nervosa. Neuropsychologia. 2012;50(5):567–75.
31. Islam MA, Fagundo AB, Arcelus J, Aguera Z, Jimenez-Murcia S, Fernandez-Real JM, et al. Olfaction in eating disorders and abnormal eating behavior: a systematic review. Front Psychol. 2015;6.
32. Kinnaird E, Stewart C, Tchanturia K. Taste sensitivity in anorexia nervosa: a systematic review. International Journal of Eating Disorders. 2018.
33. Lombion-Pouthier S, Vandel P, Nezelof S, Haffen E, Millot JL. Odor perception in patients with mood disorders. Journal of Affective Disorders. 2006;90(2-3):187–91.
34. Buron E, Bulbena A. Olfaction in affective and anxiety disorders: a review of the literature. Psychopathology. 2013;46(2):63–74.
35. Kaye WH, Bulik CM, Thornton L, Barbarich N, Masters K, Price Fcln Collaborative G. Comorbidity of anxiety disorders with anorexia and bulimia nervosa. Am J Psychiatry. 2004;161(12):2215–21.
36. Salbach-Andrae H, Lenz K, Simmendinger N, Klinkowski N, Lehmkuhl U, Pfeiffer E. Psychiatric comorbidities among female adolescents with anorexia nervosa. Child Psychiatry and Human Development. 2008;39(3):261–72.
37. Bentz M, Guldberg J, Vangkilde S, Pedersen T, Plessen KJ, Jepsen JR. Heightened olfactory sensitivity in young females with recent-onset anorexia nervosa and recovered individuals. PLoS One. 2017;12(1):e0169183.
38. Tonacci A, Calderoni S, Billeci L, Maestro S, Fantozzi P, Ciuccolli F, et al. Autistic traits impact on olfactory processing in adolescent girls with anorexia nervosa restricting type. Psychiatry Res. 2019;274:20–6.
39. First M, Williams J, Karg R, Spitzer R. Structured clinical interview for DSM-5, Research Version. Arlington, VA: American Psychiatric Association; 2015.
40. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. Journal of Autism and Developmental Disorders. 2001;31(1):5–17.
41. Hummel T, Sekinger B, Wolf SR, Pauli E, Kobal G. 'Sniffin' Sticks': olfactory performance assessed by the combined testing of odor identification, odor discrimination and olfactory threshold. Chemical Senses. 1997;22(1):39–52.
42. Mueller C, Kallert S, Renner B, Stiassny K, Temmel AFP, Hummel T, et al. Quantitative assessment of gustatory function in a clinical context using impregnated "taste strips". Rhinology. 2003;41(1):2–6.
43. Tavassoli T, Hoekstra RA, Baron-Cohen S. The sensory perception quotient (SPQ): development and validation of a new sensory questionnaire for adults with and without autism. Molecular Autism. 2014;5(1):29.
44. Ashwood KL, Gillan N, Horder J, Hayward H, Woodhouse E, McEwen FS, et al. Predicting the diagnosis of autism in adults using the autism-spectrum quotient (AQ) questionnaire. Psychological medicine. 2016;46(12):2595–604.
45. Sizoo BB, Horwitz EH, Teunisse JP, Kan CC, Visers C, Forceville EJM, et al. Predictive validity of self-report questionnaires in the assessment of autism spectrum disorders in adults. Autism. 2015;19(7):842–9.
46. Conner CM, Cramer RD, McGonigle JJ. Examining the diagnostic validity of autism measures among adults in an outpatient clinic sample. Autism in Adulthood. 2019;1(1):60–8.
47. Westwood H, Eisler I, Mandy W, Leppanen J, Treasure J, Tchanturia K. Using the autism-spectrum quotient to measure autistic traits in anorexia nervosa: a systematic review and meta-analysis. Journal of Autism and Developmental Disorders. 2016;46(8):964–77.
48. Fairburn CG, Beglin S-J. Eating disorder examination questionnaire (EDE-Q 6.0). In: Fairburn CG, editor. Cognitive behaviour therapy and eating disorders. New York: Guilford Press; 2008.
49. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatrica Scandinavica. 1983;67(6):361–70.
50. Muratori F, Tonacci A, Billeci L, Catalucci T, Igliozzi R, Calderoni S, et al. Olfactory processing in male children with autism: atypical odor threshold and identification. Journal of Autism and Developmental Disorders. 2017;47(10):3243–51.
51. Cameron EL. Olfactory perception in children. World J Otorhinolaryngol Head Neck Surg. 2018;4(1):57–66.
52. Mullol J, Alobid I, Mariño-Sánchez F, Quintó L, de Haro J, Bernal-Sprekelsen M, et al. Furthering the understanding of olfaction, prevalence of loss of smell and risk factors: a population-based survey (OLFACAT study). BMJ Open. 2012;2(6):e001256.
53. Boyce JM, Shone GR. Effects of ageing on smell and taste. Postgrad Med J. 2006;82(966):239–41.

54. Haase L, Green E, Murphy C. Males and females show differential brain activation to taste when hungry and sated in gustatory and reward areas. Appetite. 2011;57(2):421–34.
55. Sorokowski P, Karwowski M, Misiak M, Marczak MK, Dziekan M, Hummel T, et al. Sex differences in human olfaction: a meta-analysis. Frontiers in Psychology. 2019;10:242.
56. Duclova J, Hrdlicka M. Olfactory functions are not associated with autism severity in autism spectrum disorders. Neuropsychiatric disease and treatment. 2013;9:1847–51.
57. Ashwin C, Chapman E, Howells J, Rhydderch D, Walker I, Baron-Cohen S. Enhanced olfactory sensitivity in autism spectrum conditions. Molecular Autism. 2014;5(1):53.
58. Neil L, Olsson NC, Pellicano E. The relationship between intolerance of uncertainty, sensory sensitivities, and anxiety in autistic and typically developing children. Journal of Autism and Developmental Disorders. 2016;46(6):1962–73.
59. Hollocks M J, Lerh JW, Magiati I, Meiser-Stedman R, Brugha TS. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. Psychological Medicine. 2018;49(4):559–72.
60. Tchanturia K, Smith E, Weineck F, Fidanboylu E, Kern N, Treasure J, et al. Exploring autistic traits in anorexia: a clinical study. Molecular Autism. 2013;4.
61. Zucker NL, Merwin RM, Bulik CM, Moskovich A, Wildes JE, Grob J. Subjective experience of sensation in anorexia nervosa. Behav Res Ther. 2013;51(6):256–65.
62. Brand-Gothelf A, Parush S, Eitan Y, Admoni S, Gur E, Stein D. Sensory modulation disorder symptoms in anoredia nervosa and bulimia nervosa: a pilot study. International Journal of Eating Disorders. 2016;49(1):59–68.
63. Crucianelli L, Card V, Treasure J, Jenkinson PM, Fotopoulou A. The perception of affective touch in anoredia nervosa. Psychiatry Res. 2016;239:72–8.
64. Gates S, Ealing E. Reporting and interpretation of results from clinical trials that did not claim a treatment difference: survey of four general medical journals. BMJ Open. 2018;9:e024785.
65. Aschenbrenner K, Scholze N, Joraschky P, Hummel T. Gustatory and olfactory sensitivity in patients with anorexia and bulimia in the course of treatment. J Psychiatr. Res. 2008;43(2):129–37.
66. Dazzi F, De Nitto S, Zamberti G, Loriedo C, Clofalo A. Alterations of the olfactory-gustatory functions in patients with eating disorders. Eur. Eat. Disorders. Rev. 2013;21:382–5.

Publisher's Note

11.1 Supplementary Material

This file includes the results tables for secondary analyses run to control for potential confounders following initial group comparisons.

Comparisons were rerun to exclude people who had ever smoked from each group (removing *n*= 10 HC, and *n*= 10 people with AN). This did not alter the direction of results (Table S1).

Table S1

Taste and smell group outcomes, adjusted for smoking status.

	HC mean (*SD*) (*n*=30)	**AN mean (*SD*) (*n*=30)**	**Test statistic**	***p***
Odour Total	36.28 (3.90)	35.33 (4.13)	*t*(58)= 0.92	0.364
Odour Threshold	10.22 (2.74)	10.87 (2.77)	*t*(58)= -0.92	0.364
Odour Discrimination	12.67 (1.60)	11.87 (1.52)	*t*(58)= 1.27	0.208
Odour Identification	13.40 (2.01)	12.60 (1.59)	*t*(58)= 2.17	0.034
	HC mean (*SD*) (*n*=30)	**AN mean (*SD*) (*n*=29)**		
Taste Total	13(5)	11(5)	*U*= 335.5	0.129

Sweet*	3.5 (1.5)	4 (1)	*U*= 425.5	0.874
Sour	2.33 (1.21)	1.66 (1.29)	*t*(57)= 2.08	0.042
Salty*	4 (1)	3 (1)	*U*=384.5	0.407
Bitter*	3 (1)	3 (2)	*U*= 346.5	0.161

To control for the potential role of medication use on sensory outcomes, the AN group was split into two sub-groups: 1) those taking psychiatric medication (*n*= 25) and 2) those not taking psychiatric medication (*n*= 15). These sub-groups were then compared on each measure (Table S2).

Table S2

Taste and smell group outcomes, comparing people with AN based on psychiatric medication use.

	AN medication mean (*SD*) (*n*=25)	**AN no medication mean (*SD*) (*n*=15)**	**Test statistic**	***p***
Odour Total	35.94 (4.23)	35.30 (4.68)	*t*(38)= -0.45	0.659
Odour Threshold	10.66 (2.75)	11.03 (3.06)	*t*(38)= 0.40	0.693
Odour Discrimination	12.40 (1.78)	11.73 (3.10)	*t*(38)= -0.47	0.641
Odour Identification	12.88 (1.54)	12.53 (1.96)	*t*(38)= -0.49	0.625

	AN medication mean (*SD*) (*n*=24)	**AN no medication mean (*SD*) (*n*=15)**		
Taste Total*	11.5 (4)	11 (6)	*U*= 172	0.816
Sweet*	4 (1)	4 (1)	*U*= 174	0.848
Sour	1.58 (1.47)	2.2 (0.86)	*t*(37)= 1.47	0.150
Salty*	4 (1)	3 (1)	*U*= 160.5	0.540
Bitter*	3 (2)	3 (1)	*U*= 151	0.385

An ANCOVA was performed on the smell outcomes to control for the independent contributions of anxiety to group comparisons (Table S3).

Table S3

Smell outcomes adjusted for heightened levels of anxiety in the AN group.

	Adjusted HC mean (*95% CI*)	**Adjusted AN mean (*95% CI*)**	**Test statistic**	***p***
Odour Total	36.91 (35.38-38.45)	34.87 (33.34-36.41)	*F*(1, 78)= 2.78	0.099
Odour Threshold	10.09 (8.99-11.20)	10.52 (9.41-11.62)	*F*(1, 78)= 2.10	0.630
Odour Discrimination	13.44 (12.70-14.18)	11.72 (10.98-12.46)	*F*(1, 78)= 6.32	0.014

Odour Identification	13.39 (12.74-14.03)	12.64 (12.00-13.28)	*F*(1, 78)= 2.11	0.151

An ANCOVA was performed on the smell outcomes to control for the independent contributions of autistic traits to group comparisons (Table S4).

Table S4

Smell outcomes adjusted for heightened levels of autistic traits in the AN group.

	Adjusted HC mean (*95% CI*)	**Adjusted AN mean (*95% CI*)**	**Test statistic**	***p***
Odour Total	36.00 (34.54-37.46)	35.98 (34.52-37.44)	*F*(1, 80)= 0.00	0.984
Odour Threshold	9.93 (8.90-10.97)	10.75 (9.72-11.78)	*F*(1, 80)= 1.06	0.307
Odour Discrimination	12.86 (12.15-13.57)	12.27 (11.56-12.98)	*F*(1, 80)= 0.76	0.387
Odour Identification	13.21 (12.61-13.82)	12.96 (12.36-13.57)	*F*(1, 80)= 0.48	0.491

Chapter 12: Interoception in anorexia nervosa: Exploring associations with alexithymia and autistic traits

Kinnaird, E., Stewart, C. & Tchanturia, K. (2020b). Interoception in Anorexia Nervosa: Exploring Associations With Alexithymia and Autistic Traits. *Frontiers in Psychiatry*. doi:10.3389/fpsyt.2020.00064

frontiers in Psychiatry

ORIGINAL RESEARCH
published: 21 February 2020
doi: 10.3389/fpsyt.2020.00064

Interoception in Anorexia Nervosa: Exploring Associations With Alexithymia and Autistic Traits

Emma Kinnaird[1], *Catherine Stewart*[2] *and Kate Tchanturia*[3,4]*

[1] King's College London, London, United Kingdom, [2] Maudsley Centre for Child and Adolescent Eating Disorders, South London and Maudsley NHS Foundation Trust, London, United Kingdom, [3] Eating Disorders, South London and Maudsley NHS Foundation Trust, London, United Kingdom, [4] Department of Psychology, Ilia State University, Tbilisi, Georgia

OPEN ACCESS

Edited by:
Damien Brevers,
University of Luxembourg,
Luxembourg

Reviewed by:
Sahib S. Khalsa,
Laureate Institute for Brain Research,
United States
Olivier Desmedt,
Université catholique de Louvain,
Belgium

***Correspondence:**
Kate Tchanturia
kate.tchanturia@kcl.ac.uk

Specialty section:
This article was submitted to Psychopathology, a section of the journal Frontiers in Psychiatry

Received: 03 December 2019
Accepted: 24 January 2020
Published: 21 February 2020

Citation:
Kinnaird E, Stewart C and Tchanturia K (2020) Interoception in Anorexia Nervosa: Exploring Associations With Alexithymia and Autistic Traits. Front. Psychiatry 11:64. doi: 10.3389/fpsyt.2020.00064

Background: Previous research on whether interoception is altered in anorexia nervosa (AN) using the heartbeat tracking task has yielded inconsistent results. However, no previous research has examined whether interoception is associated with alexithymia and autistic traits in AN, conditions which are more prevalent in this population and thought to be related to performance in this task. The aim of this study was to explore whether altered interoception in AN is associated with alexithymia and autistic traits.

Methods: We assessed interoceptive accuracy using the heartbeat tracking task in n = 37 people with AN, and n = 37 age and gender matched healthy controls (HC), and explored within the AN group if interoceptive accuracy was related to self-rated alexithymia or autistic traits. We also assessed self-reported interoceptive ability, and the relationship between subjective and actual performance.

Results: Heartbeat tracking task performance was not found to be altered in the AN group compared to the HC group. However, confidence ratings in task performance in the AN group were lower compared to the HC group. Unlike the HC group, confidence ratings in the AN group did not correlate with task performance. Within the AN group there was no relationship between interoceptive accuracy, alexithymia, and autistic traits, after controlling for the potential confounders of anxiety and depression. There was a relationship between confidence ratings and illness severity in the AN group.

Conclusion: The results found no differences between heartbeat tracking task performance in people with AN compared to HC. There was no association between task performance, alexithymia and autistic traits in AN. Results do suggest that people with AN exhibit lowered confidence in their task performance, and that they may lack insight into this performance compared to HC. The findings are discussed in the context of potential significant limitations of the heartbeat tracking task, with recommendations for future research into interoception in AN.

Keywords: anorexia nervosa, eating disorders, autism, alexithymia, interoception

INTRODUCTION

Anorexia nervosa (AN) is an eating disorder (ED) characterized by the restriction of energy intake resulting in low body weight, a resistance to weight gain, and altered body image (1). Early research on AN suggested that this food restriction, and associated symptoms such as altered body image and problems identifying emotions, may be driven by a difficulty detecting internal bodily sensations (2). This concept of sensitivity to bodily stimuli has come to be understood under the wider term of interoception, or "the sense of the physiological condition of the entire body" (3). Interoception encompasses how the brain identifies, interprets and integrates internal stimuli. Altered interoception is associated with a number of processes thought to be related to the development and maintenance of AN, including appetite regulation, emotion regulation, self-awareness, and motivation (3–6). Research into interoception has encompassed various definitions of key terms, including similar terms being used by different studies to describe different concepts (7). Recently, Garfinkel and co-authors (8) have defined interoceptive accuracy (objective ability to detect internal stimuli), interoceptive sensibility (self-perceived ability to detect internal stimuli), and an individual's metacognitive insight into their objective ability. The current study will use these definitions when discussing different aspects of interoception, including when referring to previous research which used different terms.

Studies on whether interoceptive accuracy is altered in AN have yielded mixed findings. Although earlier research often focused on hunger and satiety detection, more recent studies on interoceptive accuracy in AN have most commonly used measures of cardiac interoception, specifically the heartbeat tracking task (9). Using the heartbeat tracking task, two initial studies found that people with AN had lower interoceptive accuracy (10, 11). By contrast, three more recent studies using the same measure found no significant differences between people with AN and healthy controls (HC) (12–14). One previous study has used a heartbeat discrimination task, finding no differences between people with AN and HC (15). By contrast, research on interoceptive sensibility in AN consistently suggests that people with AN self-report a lack of confidence in their ability to detect their internal stimuli compared to HC (16). It should be noted that these previous interoceptive sensibility studies have primarily used the interoceptive subscale of the Eating Disorder Inventory (EDI) (17). This subscale has been criticized for potentially measuring emotional, rather than somatic awareness (15), for not distinguishing between a lack of acceptance of emotional arousal, and a lack of clarity surrounding internal stimuli (18). The subscale also primarily focuses on the sensations of hunger and satiety, rather than including a range of different body sensations (13).

Therefore, previous research suggests that while people with AN self-report a lowered ability to detect internal stimuli, it is unclear whether this equates to objectively lowered interoceptive accuracy. One potential reason for this variability in previous findings is the methodology. The majority of studies on interoceptive accuracy in AN have used the heartbeat tracking task, but this method has come under increasing scrutiny. Heartbeat tracking can be influenced by a number of factors, including BMI (19), cardiac variables (20), and prior knowledge about typical heart rates (21). It has also been suggested that heartbeat tracking scores reflect participant beliefs about heart rate, rather than actual counted heartbeat sensations (22, 23). In addition, the test has low test-retest reliability, and does not relate to other measures of cardiac interoception (24, 25). An additional difficulty in using this test to measure interoceptive accuracy in AN is the potential influence of related clinical variables. For example, previous research has considered the role of depression and anxiety when exploring this area, variables known to be associated with altered interoceptive accuracy (11, 12, 26, 27). However, to date, no research has explored whether there is an association between alexithymia, autistic traits and interoception in AN.

Autism is a neurodevelopmental disorder associated with differences in social communication, and restricted behaviours and interests (1). People with AN exhibit heightened levels of autistic traits compared to HC (28), and qualitative research suggest that altered interoception could contribute to disordered eating in autistic adults (29, 30). Research suggests that interoceptive accuracy may be lowered in autism (31, 32), although other studies have found no differences in autism compared to HC (33–35).

It has been suggested that apparent differences in interoceptive accuracy in autism could in fact be related to the higher levels of alexithymia seen in autistic populations (36–40). Alexithymia is associated with lower interoceptive accuracy, to the extent that it has been hypothesised to be the product of impaired interoception (21, 41, 42). Furthermore, this relationship may be specific to clinical populations: a recent meta-analysis found no relationship between interoception in control populations, but found that lowered interoception was related to heightened alexithymia in EDs and autism (43). However, this study used a broad definition of interoception, described as "interoceptive awareness," including attention, detection, magnitude, discrimination, accuracy, insight, sensibility, and self-report abilities surrounding bodily cues (7). Therefore, the findings related to a broadly defined construct of interoception, incorporating a number of different measurement approaches. Moreover, the meta-analysis considered EDs as a single category rather than distinguishing between AN, bulimia nervosa (BN) and binge eating. No previous study has specifically investigated the relationship between interoceptive accuracy as measured using the heartbeat tracking task and alexithymia in AN.

Therefore, any attempt to investigate the associations between autistic traits and interoception in AN would also require a consideration of the role of alexithymia, with research suggesting alexithymia is heightened in people with AN (44). However, to date the associations between different facets of interoception, alexithymia, and autism in AN have not been explored. The aim of this exploratory study was to address this gap in the literature by investigating the following hypotheses using the heartbeat tracking task:

1. People with AN would exhibit lowered interoceptive accuracy compared to HC.

2. People with AN would self-report lowered interoceptive sensibility compared to HC.
3. People with AN would exhibit poorer metacognitive insight into their task performance compared to HC.
4. There would be an association between interoceptive accuracy, alexithymia and autism within the AN group.

In the context of a lack of previous research in this area, the current study only examined associations between interoceptive accuracy, alexithymia, and autistic traits in AN. It does not present hypotheses surrounding the expected relationships.

METHODS

Participants

Participants with AN (n = 37) were recruited from a specialist ED treatment service. Additional participants were recruited by advertising online with a UK-based ED charity. All participants met DSM-V criteria for AN as assessed using the Structured Clinical Interview for DSM [SCID-5 (45)]. Participants were excluded if they reported a neurological condition or serious medical condition. Participants with AN were included if they had a previous diagnosis of autism.

Age and gender matched HC (n = 37) were recruited through the local university and through advertising online. Exclusion criteria for HC included any history of EDs or mental health conditions, neurological or serious medical conditions, or a prior diagnosis of autism. These were confirmed through screening using the SCID-5 and the Autism Spectrum Quotient (46). Participants received £20 for taking part in the study.

Measures and Procedure

Interoceptive Accuracy

Interoceptive accuracy was assessed using a heartbeat tracking task, which requires participants to detect their own heartbeats (9). Participants were asked to silently count their heartbeats during four randomised time windows (25, 35, 45, and 100 s), and then at the end of each window to report the number of counted heartbeats to the researcher. Participants were verbally cued to begin counting by the researcher, and then cued to stop counting when a timer alarm sounded. Participants then verbally reported the number of heartbeats counted. Actual number of heartbeats were measured using a pulse oximeter with the sensor attached to their index finger. An interoceptive accuracy score was calculated for each time trial for each participant using the formula 1 − (|nbeatsreal − nbeatsreported|)/((nbeatsreal + nbeatsreported)/2), with resulting scores averaged across the four trials to give an overall score for each participant (8).

Although the efficacy of the heartbeat tracking task as a measure of interoceptive accuracy has recently come under scrutiny, this task was chosen as it has been used in the vast majority of previous research on interoceptive accuracy in AN, alexithymia and autism (22, 47). As the aim of this study was to explore whether heartbeat tracking task performance could be related to alexithymia and autistic traits in AN, the current study has continued to use this method.

Interoceptive Sensibility

In the context of previous criticism of the EDI interoceptive subscale (13, 15, 18), interoceptive sensibility was assessed using total scores on the awareness subscale of the Porges Body Perception Questionnaire [BPQ (48)]. The subscale uses 45 questions to assess self-reported awareness of bodily symptoms, with participants answering on a Likert Scale from "never" to "always." A higher score indicates higher interoceptive sensibility. The subscale has previously been used in interoception research, including in autistic populations, but has not previously been used in people with AN (8, 31). A recent meta-analysis found that the BPQ was significantly positively associated with alexithymia (43).

Interoceptive sensibility was additionally assessed using task confidence ratings: immediately following the heartbeat tracking task, participants were asked to rate how confident they were in their task performance on a scale from 1 (least confident) to 100 (most confident).

Metacognitive Insight

Metacognitive insight into performance was operationalized as the correspondence between interoceptive accuracy (heartbeat tracking task) and interoceptive sensibility [BPQ and confidence ratings (7, 49)]. In the present study this was measured as group correlations between heartbeat tracking scores, and BPQ and confidence ratings.

Clinical Variables

Alexithymia was measured using the Toronto Alexithymia Scale [TAS-20) (50)]. The TAS-20 is a self-report measure of alexithymia (the inability to label and describe emotions in the self) with good internal consistency and test-retest reliability. A higher score indicates higher levels of alexithymia. The TAS-20 is widely used in research in both autistic and ED populations (37, 44).

Autistic traits were measured using the Autism Spectrum Quotient [AQ) (6)]. The AQ is a continuous measure of autistic traits, with higher scores indicating higher levels of autistic traits. The AQ has previously been used in AN populations, with people with AN typically scoring higher compared to HC (28). Whilst the AQ does include a cut-off score, with scores above 32 indicating potentially clinically significant levels of autistic traits, recent research has questioned the ability of the AQ to distinguish "true" autism cases in populations with high levels of autistic traits (51–53). Consequently, beyond screening HC for high autistic traits at the beginning of the study, the AQ was only used in the analysis as a continuous measure.

Previous research has suggested that the relationship between alexithymia, autism and interoceptive accuracy cannot be successfully measured without accounting for the role of anxiety and depression (47). Therefore, anxiety and depression were measured using the Hospital Anxiety and Depression Scale [HADS (54)]. The HADS is a widely used 14-item self-rating instrument for anxiety and depression. The clinical threshold is 10 for each scale.

Procedure

The study received ethical approval from North East - Newcastle & North Tyneside 2 Research Ethics Committee (18/NE/0193).

All subjects gave written informed consent in accordance with the Declaration of Helsinki. All testing took place during a single study visit. Following informed consent, participants completed questionnaires and self-reported demographic information. Height and weight were measured on the day of testing to assess BMI scores. If a participant with AN was currently in treatment, their BMI was taken from their most recent measurements in clinical notes. Participants with AN additionally self-reported their illness duration. Participants then completed the heartbeat tracking task, and rated their confidence in their task performance. A small number of participants did not complete all questionnaires but did complete all screening measures and experimental tasks; any difference in group numbers across each self-report measure has been highlighted in the results.

Analysis

Statistical analyses were performed using Stata (version 15.0) software. Interoceptive accuracy scores were calculated for each of the time intervals, and averaged to give an overall score. Mean heart rate (MHR) was assessed by calculating the participant's heart rate across each time trial, and then averaging the data to give an overall MHR estimate.

The variables age and interoceptive sensibility (BPQ scores) were found to be nonnormally distributed and were transformed. The following variables were found to be nonnormally distributed and could not be transformed: BMI, EDE Global scores, HADS depression, interoceptive accuracy scores, and confidence in task performance scores. In addition to the nonnormal distribution, interoceptive accuracy scores were found to be highly skewed (skewness = −1.39, kurtosis = 5.32). Therefore, nonnormally distributed variables were analysed using nonparametric tests, and are summarized in the results using median and interquartile range (*IQR*) values instead of means and standard deviations (*SD*).

Group differences on each variable were calculated using *t*-tests, or Mann-Whitney U tests for nonparametric variables that could not be transformed. Correlations were performed within each group to establish relationships between the heartbeat tracking task, and the BPQ and confidence ratings.

Within the AN group only, a multiple linear regression analysis was performed with interoceptive accuracy (overall mean score) as the dependent variable to explore the relative contributions of autistic traits and alexithymia, while also controlling for the role of anxiety and depression as recommended by previous research (21). Correlational analyses were performed to assess relationships between confidence scores and clinical variables in the AN group.

RESULTS

Clinical and Demographic Characteristics

In the AN group (n = 37), 31 participants had restrictive AN (83.78%), while 6 participants had binge/purge AN (16.22%). Mean illness duration was 9.41 years (*SD* 7.72). Twenty-nine participants were receiving treatment for their AN at the time of study participation (78.38%), and eight participants were not receiving treatment (21.62%). Of the participants receiving treatment, the majority (n = 23, 62.16%) were receiving outpatient treatment, and a minority (n = 6, 16.22%) were in inpatient treatment. Twenty-four participants with AN (64.86%) were taking psychotropic medication. Three participants with AN reported a prior diagnosis of autism. In addition, the majority (n = 24, 64.86%) of participants in the AN group reported at least one comorbid clinical diagnosis. The most common clinical diagnoses were depression (n = 15) and anxiety (n = 10), and n = 5 participants reported a diagnosis of borderline personality disorder. Diagnoses reported by only one participant were bipolar disorder, obsessive-compulsive disorder, and posttraumatic stress disorder.

Group differences are summarized in **Table 1**. Participants were matched on age and gender, and exhibited no differences in MHR. As expected, participants with AN had lower mean BMIs compared to the HC group, and scored higher on measures of alexithymia, ED symptomatology, autistic traits, depression, and anxiety.

Interoceptive Accuracy

Heartbeat tracking scores are summarized in **Table 2**. There were no significant differences between groups on the overall heartbeat tracking score, or at any time point, with small effect sizes.

Interoceptive Sensibility

There were no significant differences between groups in interoceptive sensibility as measured by the BPQ (HC mean= 117.61 (n = 36, *SD* = 43.00), AN mean= 115.43 (n = 37, *SD* = 24.49), $t(71) = 0.21$, $p = 0.833$, $d = 0.05$). The AN group did score significantly lower on their confidence rating in their interoceptive accuracy task performance, with a medium effect size (HC median = 50, *IQR* = 43.00, AN median = 40, *IQR* = 38), $U = 477.5$, $p = 0.025$, $d = 0.54$).

TABLE 1 | Clinical and demographic group characteristics.

	HC mean (SD) (n = 37)	AN mean (SD) (n = 37)	Test statistic	p	Effect size (d)
Age (years)	26.05 (7.13)	26.08 (8.05)	$t(72) = -0.36$	0.720	0.08
Gender	n = 35 female (94.59%), n = 2 male (5.41%)	n = 35 female (94.59%), n = 2 male (5.41%)		1.00	
BMI*	22.8 (4.4)	15.8 (1.2)	$U = 0$	<0.001	3.37
Mean Heart Rate (MHR; beats per minute)	72.27 (10.12)	69.19 (11.22)	$t(72) = 1.24$	0.219	0.29
Alexithymia (TAS)	41.76 (13.45)	61.43 (13.12)	$t(72) = -6.37$	<0.001	1.48
EDE-Q Global*	0.61 (0.89)	4.22 (1.33)	$U = 10$	<0.001	3.20
AQ	12.57 (6.80)	23.30 (10.36)	$t(72) = -5.27$	<0.001	1.22
HADS Depression*	2 (3)	9 (5) n = 36	134.5	<0.001	1.89
HADS Anxiety	6.08 (3.90)	13.17 (4.21) n = 36	$t(71) = -7.46$	<0.001	1.75

*Data nonnormally distributed. Medians and interquartile ranges presented, and data analysed using nonparametric methods.

TABLE 2 | Group differences in interoceptive accuracy scores.

	HC mean (*SD*) (*n* = 37)	AN mean (*SD*) (*n* = 37)	Test statistic	*p*	Effect size (*d*)
Interoceptive Accuracy*	0.67 (0.35)	0.74 (0.28)	*U* = 580.5	0.261	0.26
25 seconds*	0.68 (0.45)	0.83 (0.35)	*U* = 507	0.055	0.46
35 seconds*	0.71 (0.58)	0.75 (0.29)	*U* = 600	0.361	0.21
45 seconds*	0.70 (0.34)	0.71 (0.38)	*U* = 667.5	0.854	0.04
100 seconds*	0.68 (0.30)	0.77 (0.29)	*U* = 586.5	0.289	0.25

*Data non-normally distributed. Medians and interquartile ranges presented.

Metacognitive Insight

In the HC group, there was no relationship between the heartbeat tracking task and BPQ scores ($r = 0.09$, $p = 0.605$). There was a significant positive correlation between heartbeat tracking scores and confidence ratings ($r = 0.60$, $p < 0.001$). By contrast, in the AN group there was no correlation between the heartbeat tracking task and the BPQ ($r = 0.17$, $p = 0.322$), or the confidence ratings ($r = 0.26$, $p = 0.117$).

Relationship With Clinical Variables

The relative contribution of autistic traits, alexithymia, anxiety, and depression to interoceptive accuracy were calculated using a regression analysis within the AN group only. There were no significant relationships between any of these clinical variables and interoceptive accuracy (**Table 3**).

Correlations between clinical variables and task confidence ratings were also explored within the AN group only. There were no significant relationships between confidence ratings and alexithymia, autistic traits, anxiety, or depression in the AN group. However, there was a significant negative relationship between confidence ratings and ED severity as measured by the EDE-Q Global score ($r = -0.41$, $p = 0.012$).

DISCUSSION

The overall aim of this study was to explore whether interoceptive accuracy as measured by the heartbeat tracking task is associated with alexithymia and autistic traits in AN. Contrary to the hypothesis that people with AN would exhibit lowered cardiac interoceptive accuracy compared to HC, the study found no significant differences between groups in heartbeat tracking performance. This is in line with a number of recent studies, including two that were published after the hypotheses for the current study were generated (12–14). The findings of the present study, and more recent research, contrast with previous research using the heartbeat tracking task in AN which found lowered accuracy in this population (10, 11). One potential explanation for this variation in findings are differences in the AN samples used in each study, such as differences in BMI, age, comorbidities, illness duration, and treatment status. For example, the participants with AN in this study were receiving a range of different treatments (inpatient, outpatient, or no treatment), compared to participants receiving self-help only in the Pollatos et al. (11) study. The participants in the current study additionally had lower BMIs, higher mean illness duration, and were slightly older compared to this initial study. This reflects concerns that heartbeat tracking task performance is associated with state-dependent factors (25). For example, Richard et al. (14) found that interoceptive accuracy was associated with inpatient treatment progress, with higher accuracy associated with higher BMIs and longer time in treatment (14).

TABLE 3 | Relative contribution of clinical variables to interoceptive accuracy within the anorexia nervosa (AN) group only.

	B	*t*	*p*
Autistic traits (AQ)	0.00	0.02	0.987
Alexithymia (TAS)	0.05	0.20	0.846
Anxiety (HADS)	−0.21	−1.10	0.278
Depression (HADS)	−0.07	−0.34	0.736

The second hypothesis of this study was that people with AN would exhibit lowered interoceptive sensibility (self-perceived interoceptive aptitude) compared to HC. Findings on interoceptive sensibility were mixed: there were no differences between groups on the BPQ, a measure of self-reported awareness of bodily symptoms, but people with AN did report lower confidence in their interoceptive task performance. The third hypothesis of this study was that people with AN would exhibit poorer metacognitive insight, operationalised as group correlations between performance and BPQ/confidence ratings. The finding that there was a positive correlation between task performance and confidence ratings in the HC group, but not the AN group, suggests that people with AN may lack insight into their interoceptive abilities (55). Significantly, lower confidence ratings were correlated with higher ED symptomatology in the AN group, indicating that this lack of insight may be related to ED severity. If individuals with AN have less confidence in their ability to detect interoceptive sensations, this could result in a reliance on other cues, such as prior beliefs around likely interoceptive responses. The possibility that people with AN rely on predicted sensations, as opposed to the detection of actual sensations, is supported by research suggesting that people with AN find it difficult to detect actual interoceptive responses from anticipated responses (55, 56). Individuals with AN were more likely to falsely endorse changes in interoceptive sensation in the absence of stimulation, and reported more intense cardiorespiratory sensations compared to HC, during pre-meal states. This prediction error between actual and anticipated responses is also thought to be altered in other conditions with heightened prevalence in AN, including autism, anxiety and depression (31, 57). Future research should consider further investigating the concept of metacognitive insight in interoception in AN, in particular the role that this might play in interoceptive prediction errors.

Alternatively, the lower confidence ratings found in this study may reflect the fact that low self-esteem is very common in people with AN (58). Therefore, the findings of this study could reflect a generalised lack of confidence in ability, rather than a lack of confidence specific to interoceptive performance. It should be noted that the current results contrast with the findings of Lutz et al. (13) who found no difference between groups in task confidence ratings (13).

Finally, the study hypothesised that there would be an association between interoceptive accuracy, alexithymia and autism within the AN group. The findings of this study did not support this hypothesis, with no relationships found. Consequently, it is possible that interoceptive accuracy is not linked to alexithymia and autistic traits in AN, and is rather associated with other drivers, such as treatment duration or BMI (14). However, it should be noted that interoceptive accuracy, autism, and alexithymia have not consistently been linked in previous studies: two recent studies have found no associations between autism and interoceptive accuracy in adults (33, 34). Similarly, two additional studies have found no association between interoceptive accuracy and alexithymia (34, 59).

It is likely that these mixed findings on the relationship between cardiac interoceptive accuracy, alexithymia, and autism, and indeed for the inconsistent results surrounding interoceptive accuracy in AN, is related to the heartbeat tracking task itself. The heartbeat tracking task was chosen for the current study as it has been used in the majority of previous research on interoceptive accuracy in AN, alexithymia, and autism. However, as previously outlined, heartbeat perception can be influenced by a number of factors beyond the control of the current study. For example, a recent study exploring alexithymia and interoceptive accuracy in a sample of 287 participants initially found no relationship, and subsequently only detected a relationship after accounting for 10 additional control variables (47). Some of these variables were accounted for in group comparisons in the present study: for example, there were no significant differences between groups on age or MHR. However, groups in the current study significantly differed on other variables, including anxiety, depression, BMI, and alexithymia. Although the present study is the one of the largest studies on interoceptive accuracy in AN to date [$n = 74$ compared to $n = 76$ in Richard et al. (14)], it was not possible to account for the potential roles of all these variables owing to the relatively small sample size limiting the ability to perform a large multivariable regression analysis. Additionally, the nonparametric distribution limited the ability to control for variables in group comparisons using ANCOVAs. Finally, the current study did not include a control task to account for the possible influence of participant beliefs about heart rates, or the possibility that they were counting time rather than heartbeats. However, a strength of the current study was that it controlled for anxiety and depression while exploring the relationship between interoceptive accuracy, alexithymia and autism in people with AN (47).

Therefore, the findings of this study should be understood in the context of the limitation that there are a number of problems associated with using the heartbeat tracking task as a measure of interoceptive accuracy. Future research in this area should consider adapting the heartbeat task to control for potential covariates identified by Murphy et al. (47), or by modifying the task instructions to instruct participants to specifically count their felt heartbeats, rather than reporting an estimate (23). Alternatively, studies on interoception in AN could move away entirely from the heartbeat tracking task to a more robust measure of interoceptive accuracy. For example, recent studies on cardiac interoception in AN have instead used bolus intravenous infusions of isoproterenol to artificially raise heartbeat and respiratory rate in a controlled manner, and then asked participants to rate their changing sensations using a dial (55, 56). While this type of methodology is more invasive compared to the heartbeat tracking task, it does allow for a more highly controlled approach.

Significantly, these studies similarly found no difference in interoceptive accuracy, but did find prediction errors made specifically in the context of meal anticipation. This appeared to be related to heightened anxiety, and atypical interoceptive representation of the heartbeat: individuals with AN located sensations in the left side of their chest in the absence of actual stimulation (56). Further research should consider exploring aspects of interoception in AN other than accuracy, including the ability to discriminate between sensations, or magnitude estimations. The finding in these studies that altered interoception is potentially specific to meal anticipation also warrants further research. In the current study, proximity of the task to meals was not considered. It is possible that task performance, particularly for AN participants, could have been influenced by task timing in relation to meal anticipation. Interestingly, in the current study people with AN did not self-report generalised problems with detecting bodily symptoms, as measured by the BPQ. Taken together with previous research suggesting elevated difficulties as measured using the EDI (16), these findings support the possibility in AN are specifically associated with hunger and satiety sensations, or sensations associated with emotion detection only, rather than representing a generalised difficulty. Future research could consider focusing on whether interoceptive differences in AN are associated with specific states, such as heightened emotional arousal, hunger and satiety, or meal anticipation.

In conclusion, the current findings indicate that there are no differences in heartbeat tracking task performance in people with AN compared to HC, and that this performance is not associated with alexithymia or autistic traits within AN populations. However, these findings are presented in the context of potentially significant limitations with the chosen methodology. The study did find that people with AN potentially exhibit lower metacognitive insight. Recommendations are made for future research in this area.

DATA AVAILABILITY STATEMENT

The datasets for this article are not publicly available because the authors do not have permission to share the participant data publicly. Data is available upon request from Principal investigator of the study KT, kate.tchanturia@kcl.ac.uk.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by North East - Newcastle & North Tyneside 2 Research Ethics Committee (18/NE/0193). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

All authors contributed to the design of the study. EK carried out data collection, and wrote the first manuscript draft. KT and CS contributed to the final manuscript. All authors read and approved the final manuscript.

FUNDING

EK was supported by a Medical Research Council Doctoral Training Partnership studentship (MR/N013700/1). KT would like to acknowledge support from MRC and MRF Child and Young Adult Mental Health (MR/R004595/1) and support from the Health foundation, an independent charity committed to bring better health care for people in the UK (Ref: AIMS ID): 1115447.

ACKNOWLEDGMENTS

The authors would like to thank the UK eating disorder charity Beat for their support with recruitment for this project.

REFERENCES

1. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders. 5th ed.* Arlington, VA: American Psychiatric Publishing (2013).
2. Bruch H. Perceptual and conceptual disturbances in Anorexia Nervosa. *Psychosom Med* (1962) 24(2):187. doi: 10.1097/00006842-196203000-00009
3. Craig AD. How do you feel? Interoception: the sense of the physiological condition of the body. *Nat Rev Neurosci* (2002) 3(8):655–66. doi: 10.1038/nrn894
4. Critchley HD, Garfinkel SN. Interoception and emotion. *Curr Opin In Psychiatry* (2017) 17:7–14. doi: 10.1016/j.copsyc.2017.04.020
5. Kaye WH, Wagner A, Fudge JL, Paulus M. Neurocircuitry of eating disorders. In: *Behavioral neurobiology of eating disorders*. New York, NY: Springer-Verlag Publishing US (2011). p. 37–57.
6. Paulus MP, Stein MB. An insular view of anxiety. *Biol Psychiatry* (2006) 60 (4):383–7. doi: 10.1016/j.biopsych.2006.03.042
7. Khalsa SS, Adolphs R, Cameron OG, Critchley HD, Davenport PW, Feinstein JS, et al. Interoception and mental health: a roadmap. *Biol Psychiatry Cogn Neurosci Neuroimaging* (2018) 3(6):501–13. doi: 10.1016/j.bpsc.2017.12.004
8. Garfinkel SN, Seth AK, Barrett AB, Suzuki K, Critchley HD. Knowing your own heart: distinguishing interoceptive accuracy from interoceptive awareness. *Biol Psychol* (2015) 104:65–74. doi: 10.1016/j.biopsycho.2014.11.004
9. Schandry R. Heart beat perception and emotional experience. *Psychophysiology* (1981) 18(4):483–8. doi: 10.1111/j.1469-8986.1981.tb02486.x
10. Pollatos O, Herbert BM, Berberich G, Zaudig M, Krauseneck T, Tsakiris M. Atypical self-focus effect on interoceptive accuracy in Anorexia Nervosa. *Front Hum Neurosci* (2016) 10:484. doi: 10.3389/fnhum.2016.00484
11. Pollatos O, Kurz AL, Albrecht J, Schreder T, Kleeman AM, Schopf V, et al. Reduced perception of bodily signals in Anorexia Nervosa. *Eating Behav* (2008) 9(4):318–88. doi: 10.1016/j.eatbeh.2008.02.001
12. Ambrosecchia M, Ardizzi M, Russo E, Ditaranto F, Speciale M, Vinai P, et al. Interoception and Autonomic Correlates during Social Interactions. Implications for Anorexia. *Front Hum Neurosci* (2017) 11:219. doi: 10.3389/fnhum.2017.00219
13. Lutz APC, Schulz A, Voderholzer U, Koch S, van Dyck Z, Vögele C. Enhanced cortical processing of cardio-afferent signals in anorexia nervosa. *Clin Neurophysiol* (2019) 130(9):1620–7. doi: 10.1016/j.clinph.2019.06.009
14. Richard A, Meule A, Georgii C, Voderholzer U, Cuntz U, Wilhelm FH, et al. Associations between interoceptive sensitivity, intuitive eating, and body mass index in patients with anorexia nervosa and normal-weight controls. *Eur Eating Disord Rev* (2019) 27(5):571–7. doi: 10.1002/erv.2676
15. Eshkevari E, Rieger E, Musiat P, Treasure J. An investigation of interoceptive sensitivity in eating disorders using a heartbeat detection task and a self-report measure. *Eur Eat Disord Rev* (2014) 22(5):383–8. doi: 10.1002/erv.2305
16. Jenkinson PM, Taylor L, Laws KR. Self-reported interoceptive deficits in eating disorders: a meta-analysis of studies using the eating disorder inventory. *J Psychosom Res* (2018) 110:38–45. doi: 10.1016/j.jpsychores.2018.04.005
17. Garner DM, Olmstead MP, Polivy J. Development and validation of a multidimensional eating disorder inventory for anorexia nervosa and bulimia. *Int J Eating Disord* (1983) 2(2):15–34. doi: 10.1002/1098-108x(198321)2:2<15::aid-eat2260020203>3.0.co;2-6
18. Merwin RM, Zucker NL, Lacy JL, Elliott CA. Interoceptive awareness in eating disorders: distinguishing lack of clarity from non-acceptance of internal experience. *Cogn Emotion* (2010) 24(5):892–902. doi: 10.1080/02699930902985845
19. Rouse CH, Jones GE, Jones KR. The effect of body composition and gender on cardiac awareness. *Psychophysiology* (1988) 25(4):400–7. doi: 10.1111/j.1469-8986.1988.tb01876.x
20. Knapp-Kline K, Kline JP. Heart rate, heart rate variability, and heartbeat detection with the method of constant stimuli: slow and steady wins the race. *Biol Psychol* (2005) 69(3):387–96. doi: 10.1016/j.biopsycho.2004.09.002
21. Murphy J, Catmur C, Bird G. Alexithymia is associated with a multidomain, multidimensional failure of interoception: Evidence from novel tests. *J Exp Psychol Gen* (2018) 147(3):398–408. doi: 10.1037/xge0000366
22. Brener J, Ring C. Towards a psychophysics of interoceptive processes: the measurement of heartbeat detection. *Philos Trans R Soc Lond Ser B Biol Sci* (2016) 371(1708):20160015. doi: 10.1098/rstb.2016.0015
23. Desmedt O, Luminet O, Corneille O. The heartbeat counting task largely involves non-interoceptive processes: evidence from both the original and an adapted counting task. *Biol Psychol* (2018) 138:185–8. doi: 10.1016/j.biopsycho.2018.09.00
24. Ring C, Brener J. Heartbeat counting is unrelated to heartbeat detection: a comparison of methods to quantify interoception. *Psychophysiology* (2018) 55 (9):e13084. doi: 10.1111/psyp.13084
25. Wittkamp MF, Bertsch K, Vogele C, Schulz A. A latent state-trait analysis of interoceptive accuracy. *Psychophysiology* (2018) 55(6):e13055. doi: 10.1111/psyp.13055
26. Dunn BD, Dalgleish T, Ogilvie AD, Lawrence AD. Heartbeat perception in depression. *Behav Res Ther* (2007) 45(8):1921–30. doi: 10.1016/j.brat.2006.09.008
27. Eley TC, Stirling L, Ehlers A, Gregory AM, Clark DM. Heart-beat perception, panic/somatic symptoms and anxiety sensitivity in children. *Behav Res Ther* (2004) 42(4):439–48. doi: 10.1016/S0005-7967(03)00152-9
28. Westwood H, Eisler I, Mandy W, Leppanen J, Treasure J, Tchanturia K. Using the autism-spectrum quotient to measure autistic traits in anorexia nervosa: a systematic review and meta-analysis. *J Autism Dev Disord* (2016) 46(3):964–77. doi: 10.1007/s10803-015-2641-0
29. Kinnaird E, Norton C, Pimblett C, Stewart C, Tchanturia K. Eating as an autistic adult: An exploratory qualitative study. *PloS One* (2019) 14(8): e0221937. doi: 10.1371/journal.pone.0221937
30. Kinnaird E, Norton C, Stewart C, Tchanturia K. Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment? *Int Rev Psychiatry* (2019) 31(4):1–10. doi: 10.1080/09540261.2018.1531831
31. Garfinkel SN, Tiley C, O'Keeffe S, Harrison NA, Seth AK, Critchley HD. Discrepancies between dimensions of interoception in autism: Implications

for emotion and anxiety. *Biol Psychol* (2016) 114:117–26. doi: 10.1016/j.biopsycho.2015.12.003
32. Palser ER, Fotopoulou A, Pellicano E, Kilner JM. The link between interoceptive processing and anxiety in children diagnosed with autism spectrum disorder: Extending adult findings into a developmental sample. *Biol Psychol* (2018) 136:13–21. doi: 10.1016/j.biopsycho.2018.05.003
33. Nicholson T, Williams D, Carpenter K, Kallitsounaki A. Interoception is impaired in children, but not adults, with autism spectrum disorder. *J Autism Dev Disord* (2019) 49(9):3625–37. doi: 10.1007/s10803-019-04079-w
34. Nicholson TM, Williams DM, Grainger C, Christensen JF, Calvo-Merino B, Gaigg SB. Interoceptive impairments do not lie at the heart of autism or alexithymia. *J Abnormal Psychol* (2018) 127(6):612–22. doi: 10.1037/abn0000370
35. Schauder KB, Mash LE, Bryant LK, Cascio CJ. Interoceptive ability and body awareness in autism spectrum disorder. *J Exp Child Psychol* (2015) 131:193–200. doi: 10.1016/j.jecp.2014.11.002
36. Brewer R, Happe F, Cook R, Bird G. Commentary on "Autism, oxytocin and interoception": Alexithymia, not Autism Spectrum Disorders, is the consequence of interoceptive failure. *Neurosci Biobehav Rev* (2015) 56:348–53. doi: 10.1016/j.neubiorev.2015.07.006
37. Kinnaird E, Stewart C, Tchanturia K. Investigating alexithymia in autism: A systematic review and meta-analysis. *Eur Psychiatry* (2019) 55:80–9. doi: 10.1016/j.eurpsy.2018.09.004
38. Livingston LA, Livingston LM. Commentary: Alexithymia, not autism, is associated with impaired interoception. *Front In Psychol* (2016) 7:1103. doi: 10.3389/fpsyg.2016.01103
39. Mul CL, Stagg SD, Herbelin B, Aspell JE. The feeling of me feeling for you: interoception, alexithymia and empathy in autism. *J Autism Dev Disord* (2018) 48(9):2953–67. doi: 10.1007/s10803-018-3564-3
40. Shah P, Hall R, Catmur C, Bird G. Alexithymia, not autism, is associated with impaired interoception. *Cortex* (2016) 81:215–20. doi: 10.1016/j.cortex.2016.03.021
41. Brewer R, Cook R, Bird G. Alexithymia: a general deficit of interoception. *R Soc Open Sci* (2016) 3(10):150664. doi: 10.1098/rsos.150664
42. Herbert BM, Herbert C, Pollatos O. On the relationship between interoceptive awareness and alexithymia: is interoceptive awareness related to emotional awareness? *J Pers* (2011) 79(5):1149–75. doi: 10.1111/j.1467-6494.2011.00717.x
43. Trevisan DA, Altschuler MR, Badgaiyan A, Carlos C, Duan S, Hamo E, et al. A meta-analysis on the relationship between interoceptive awareness and alexithymia: distinguishing interoceptive accuracy and sensibility. *J Abnormal Psychol* (2019) 128(8):765–76. doi: 10.1037/abn0000454
44. Westwood H, Kerr-Gaffney J, Stahl D, Tchanturia K. Alexithymia in eating disorders: systematic review and meta-analyses of studies using the toronto alexithymia scale. *J Psychosom Res* (2017) 99:66–81. doi: 10.1016/j.jpsychores.2017.06.007
45. First M, Williams J, Karg R, Spitzer R. *Structured Clinical Interview for DSM-5, Research Version*. Arlington, VA: American Psychiatric Association (2015).
46. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The Autism-Spectrum Quotient (AQ): evidence from asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J Autism Dev Disord* (2001) 31(1):5–17. doi: 10.1023/a:1005653411471
47. Murphy J, Brewer R, Hobson H, Catmur C, Bird G. Is alexithymia characterised by impaired interoception? Further evidence, the importance of control variables, and the problems with the Heartbeat Counting Task. *Biol Psychol* (2018) 136:189–97. doi: 10.1016/j.biopsycho.2018.05.010
48. Porges S. *Body Perception Questionnaire: laboratory of assessment development*. (1993) (Baltimore, USA: University of Maryland).
49. Murphy J, Catmur C, Bird G. Classifying individual differences in interoception: implications for the measurement of interoceptive awareness. *Psychonom Bull Rev* (2019) 26:1467–71. doi: 10.3758/s13423-019-01632-7
50. Bagby RM, Parker JDA, Taylor GJ. The twenty-item Toronto Alexithymia scale—I. Item selection and cross-validation of the factor structure. *J Psychosom Res* (1994) 38(1):23–32. doi: 10.1016/0022-3999(94)90005-1
51. Ashwood KL, Gillan N, Horder J, Hayward H, Woodhouse E, McEwen FS, et al. Predicting the diagnosis of autism in adults using the Autism-Spectrum Quotient (AQ) questionnaire. *psychol Med* (2016) 46(12):2595–604. doi: 10.1017/S0033291716001082
52. Conner CM, Cramer RD, McGonigle JJ. Examining the diagnostic validity of autism measures among adults in an outpatient clinic sample. *Autism In Adulthood* (2019) 1(1):60–8. doi: 10.1089/aut.2018.0023
53. Sizoo BB, Horwitz EH, Teunisse JP, Kan CC, Vissers C, Forceville EJM, et al. Predictive validity of self-report questionnaires in the assessment of autism spectrum disorders in adults. *Autism* (2015) 19(7):842–9. doi: 10.1177/1362361315589869
54. Zigmond AS, Snaith RP. the hospital anxiety and depression scale. *Acta Psychiatrica Scand* (1983) 67(6):361–70. doi: 10.1111/j.1600-0447.1983.tb09716.x
55. Khalsa SS, Craske MG, Li W, Vangala S, Strober M, Feusner JD. Altered interoceptive awareness in anorexia nervosa: Effects of meal anticipation, consumption and bodily arousal. *Int J Eating Disord* (2015) 48(7):889–97. doi: 10.1002/eat.22387
56. Khalsa SS, Hassanpour MS, Strober M, Craske MG, Arevian AC, Feusner JD. Interoceptive anxiety and body representation in anorexia nervosa. *Front In Psychiatry* (2018) 9:444–4. doi: 10.3389/fpsyt.2018.00444
57. Paulus MP, Stein MB. Interoception in anxiety and depression. *Brain Struct Funct* (2010) 214(5-6):451–63. doi: 10.1007/s00429-010-0258-9
58. Jacobi C, Paul T, de Zwaan M, Nutzinger DO, Dahme B. Specificity of self-concept disturbances in eating disorders. *Int J Eating Disord* (2004) 35(2):204–10. doi: 10.1002/eat.10240
59. Zamariola G, Vlemincx E, Corneille O, Luminet O. Relationship between interoceptive accuracy, interoceptive sensibility, and alexithymia. *Pers Individ Dif* (2018) 125:14–20. doi: 10.1016/j.paid.2017.12.024

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Chapter 13: Pragmatic sensory screening in anorexia nervosa and associations with autistic traits

Kinnaird, E., Dandil, Y., Li, Z., Smith, K., Pimblett, C., Agbalaya, R., Stewart, C. & Tchanturia, K. (2020). Pragmatic Sensory Screening in Anorexia Nervosa and Associations with Autistic Traits. *Journal of Clinical Medicine, 9*(4). doi:10.3390/jcm9041182.

Journal of
Clinical Medicine

MDPI

Article

Pragmatic Sensory Screening in Anorexia Nervosa and Associations with Autistic Traits

Emma Kinnaird [1], Yasemin Dandil [1,2], Zhuo Li [1], Katherine Smith [1], Caroline Pimblett [2], Rafiu Agbalaya [2], Catherine Stewart [3] and Kate Tchanturia [1,2,4,*]

1 King's College London, Department of Psychological Medicine, Institute of Psychology, Psychiatry and Neuroscience, London SE5 8AZ, UK
2 National Eating Disorders Service, South London and Maudsley NHS Foundation Trust, London BR3 3BX, UK
3 Child and Adolescent Eating Disorders Service, South London and Maudsley NHS Foundation Trust, London SE5 8AZ, UK
4 Department of Psychology, Illia State University, Tbilisi 0162, Georgia
* Correspondence: kate.tchanturia@kcl.ac.uk

Received: 10 March 2020; Accepted: 15 April 2020; Published: 20 April 2020

check for updates

Abstract: Background: Research suggests that people with anorexia nervosa (AN) experience subjective hypersensitivity to external sensations that may require consideration in treatment. These difficulties may be particularly pronounced in people with AN and high autistic traits. The purpose of this pilot study was to explore the use of a brief screening tool to assess sensory sensitivity in individuals receiving treatment for AN, and to assess if self-rated sensitivity in AN is related to autistic traits. Methods: 47 individuals receiving treatment for AN completed a brief sensory screening tool and self-rated their autistic traits. Individuals were also asked to give qualitative feedback on the screening tool. Results: People with AN and high autistic traits rated themselves as more hypersensitive compared to people with AN and low autistic traits. Feedback surrounding the use of the screener was positive. Conclusions: The results of this study suggest that the use of this screener may be beneficial in eating disorder settings to help adjust and calibrate treatment to personal needs, although further research and psychometric evaluation around the clinical use of the screener is required. The finding that people with AN and high autistic traits may experience elevated hypersensitivity also warrants further exploration in future research.

Keywords: anorexia nervosa; eating disorders; sensory sensitivity; autism

1. Introduction

Anorexia nervosa (AN) is an eating disorder (ED) characterised by the persistent restriction of energy intake, an intense fear of weight gain, and disturbance in the evaluation of weight and body shape [1]. With high levels of chronicity in this population and poor treatment response rates, there is an ongoing interest in how existing understandings of AN and related treatment approaches can be adapted [2–4]. One emerging research area is whether people with AN exhibit differences in how they experience their body and its relationship to the environment [5]. Research suggests that AN may be associated with dysregulated sensory processing of external stimuli. Questionnaire-based studies indicate that people with AN experience heightened sensory sensitivity (hypersensitivity) and are more likely to perceive these sensations as aversive, resulting in the attempted avoidance of sensory experiences [6–9]. This sensory profile has been associated with heightened levels of ED symptomatology, emotional dysregulation and body image disturbance, and appears to persist following treatment and weight restoration [7–9]. Sensory experiences, such as lower sensation seeking,

are also linked to heightened feelings of self-disgust in this population [6]. It is therefore possible that the core symptom of food restriction in AN may in fact play a role in self-regulating distressing sensory experiences through avoidance. Alternatively, if people with AN have low tolerance of sensory signals, then this may limit their ability to use these sensations to inform their behaviour, or to self-regulate [8].

Whilst questionnaire-based studies consistently suggest hypersensitivity in AN, biological-based findings are more mixed. Recent systematic reviews of taste and smell experiments in this population have identified evidence for both hypersensitivity and hyposensitivity (lowered sensitivity) [10,11]. This apparent discrepancy between subjective and objective measures suggests that sensory dysregulation in AN may not only be driven by potential bottom-up alterations in biological sensitivity, but also by top-down processes in how this information is perceived, interpreted and integrated [5].

Sensory difficulties may be particularly central in understanding the presentation of AN in patients with high autistic traits. Autism is a neurodevelopmental disorder associated with difficulties in social communication, repetitive and/or restrictive behaviours and interests, and sensory problems [1]. Sensory difficulties are very common in autism, with around 95% of autistic adults self-reporting altered sensory processing [12]. Significantly around one in four people with AN present with high levels of autistic traits, and around one in ten people with AN meet criteria for an autism diagnosis [13–15]. Research suggests that autistic traits in AN may be associated with longer illness durations and poorer treatment outcomes, suggesting that treatment adaptations may be required. Recent qualitative research suggests that people with AN and high autistic traits may particularly benefit from adaptations addressing sensory difficulties associated with autism [16–19]. This research indicates that that sensory difficulties in autism may impact AN and its treatment in two key ways: firstly, food-related sensitivities such as an aversion to certain textures may motivate food avoidance [20–22]. Secondly, patients with high autistic traits may find ED service environments aversive: for example, an individual with hypersensitivity to sound may find loud treatment spaces overwhelming [20].

Therefore, people with AN- and people with AN and high autistic traits in particular- may benefit from an assessment of their sensory needs during treatment. For example, if an individual presents with a strong aversion to certain tastes, these could be addressed by working with a dietician to create a meal plan that adapts around these sensitivities. At present, sensory assessments in ED services are typically carried out by a trained occupational therapist. Existing self-report assessments of sensory sensitivity, such as the Adult Sensory Profile, are often lengthy and not always freely available [23]. In this context, clinicians treating this population could benefit from the use of a brief screening tool that assesses potential sensory difficulties. A screening approach could then be used to inform whether a more detailed assessment and treatment adaptations are required.

The aim of the current study was to pilot and explore the use and acceptability of a brief, pragmatic sensory screener in a national ED service. The secondary aim of the study was to explore whether self-rated sensory sensitivities in AN are related to autistic traits.

2. Experimental Section

2.1. Participants

Adult patients with a diagnosis of AN in the South London and Maudsley National Health Service (NHS) Foundation Trust National ED Service completed the measures as part of standard audit data collection in the service. Diagnoses of AN were made by trained clinicians upon admission to the treatment programme. A total of 47 patients completed all of the measures.

2.2. Materials

2.2.1. Clinical and Demographic Information

Information on participant age, diagnosis, duration of ED, and body mass index (BMI) upon admission were taken from patient clinical notes.

2.2.2. Brief Sensory Screener

A copy of the screener is located in the Supplementary Materials for this paper (Table S1). The development of the screener was based on the five basic senses: vision, hearing, smell, taste and touch. Other senses, such as interoception or proprioception, were not included to keep the measure accessible to individuals who may not be familiar with these other modalities. Participants were presented with visual scales for each sensory modality ranging from 0 (hyposensitive) to 10 (hypersensitive), and asked to indicate their sensory level on each scale. A score of 5 indicates no sensory differences. Examples of hyposensitivity and hypersensitivity are given for each modality, with hyposensitivity (under-sensitivity) and hypersensitivity (high sensitivity) defined at the beginning of the screener.

Following an initial pilot of the screener, clinicians and patients suggested that the "touch" modality was overly broad. They suggested that a screening tool for this population could benefit from separating wider domains of touch from food textures. Therefore, the final version includes separate rating scales for touch (with examples based on fabric textures) and texture (with examples based on food textures). A number of participants only completed the first version of the questionnaire, without the separate texture scale. These participants have been included in the current study, with variation in group numbers highlighted in the results.

2.2.3. Item Autism Quotient (AQ-10)

The AQ-10 (adult version) is an autism screening tool recommended for use in adults with suspected high autistic traits [24]. It is a self-report tool consisting of 10 items, with a score of 6 and above indicating that an individual should be considered for a specialist autism assessment. This measure is widely used in this population, including for audit purposes [25,26].

2.2.4. Hospital Anxiety and Depression Scale (HADS)

The HADS is a brief 14-item self-rating measure of anxiety and depression [27]. It consists of a subscale for anxiety, and a subscale for depression, with a score of 11 and above for each subscale indicating moderate to severe symptoms.

2.3. *Procedure*

Patients admitted to day-patient and inpatient ED services at the South London and Maudsley NHS Foundation Trust routinely complete the AQ-10 and HADS upon admission as part of standard audit data collection. Patients were additionally asked to complete the sensory screener, and to write down any feedback about the screener. This study was carried out as part of a clinical innovation project approved by the Clinical Governance and Audit Committee in South London and Maudsley NHS Trust (032019) in April 2019.

2.4. *Analysis*

Participants were divided into two groups depending on whether they scored above threshold on the AQ-10. Individuals scoring below threshold were classified as having low autistic traits (LAT), and individuals scoring above threshold were classified as having high autistic traits (HAT). Shapiro-Wilk tests confirmed that the sensory outcomes were normally distributed. Although sample sizes in each group were uneven, Levene's tests suggested that the sample variances were equal on the sensory outcomes. Therefore, independent *t*-tests were used to compare groups on demographic and clinical characteristics. Categorical variables were compared using the chi square test. Sensory screener data were also analysed using independent *t*-tests. Cohen's *d* was used to calculate effect sizes. Across the whole sample, relationships between sensory outcomes and autistic traits, anxiety and depression were explored using a regression analysis. The screener was evaluated using Cronbach's alpha to calculate the internal consistency, and by soliciting written feedback from participants.

3. Results

3.1. Participant Characteristics

A total of 47 participants completed all measures. 30 participants scored below threshold on the AQ-10, forming the LAT group, and 17 participants scored above threshold to form the HAT group. Group clinical and demographic characteristics are summarised in Table 1. There were no significant differences between groups regarding their mean age, illness duration, HADS scores, or sex composition. By design the HAT group had significantly higher AQ-10 scores compared to the LAT group.

Table 1. Summary of group differences on clinical and demographic characteristics.

	LAT ($n = 30$)	HAT ($n = 17$)	t-Test ($df = 45$)	p	d
Age (Years)	30.23 (9.60)	27.76 (10.08)	0.83	0.410	0.25
Sex	96.67% female	88.24% female	$X^2 = 1.29$	0.256	-
AN Subtype	93.33% AN-R 6.67% AN-BP	93.75% AN-R 6.25% AN-BP	$X^2 = 0.03$	0.957	-
Illness duration (Years)	11.08 (8.77)	8.73 (9.32)	0.76	0.451	0.26
BMI	14.41 (2.02)	14.55 (1.67)	−0.23	0.821	0.07
AQ-10	3.60 (1.40)	7.59 (1.12)	−10.02	<0.001	3.04
HADS Anxiety	13.97 (4.70)	13.71 (6.69)	0.015	0.878	0.05
HADS Depression	11.21 (4.69)	11.82 (5.04)	−0.42	0.677	0.13

Group differences are presented as group means, with standard deviations in parentheses. Low autistic traits group (LAT), high autistic traits group (HAT), degrees of freedom (df), anorexia nervosa (AN), restrictive subtype (AN-R), binge-purge subtype (AN-BP), Adult Autism Quotient 10 item (AQ-10), Hospital Anxiety and Depression Scale (HADS), cohen's d (d), chi square (X^2).

3.2. Sensory Screener

Group scores on the sensory screeners are summarised in Table 2. Patients with AN in the HAT group self-rated themselves as significantly more hypersensitive with medium-large effect sizes in the modalities of smell, vision, texture, and total screening scores, compared to LAT patients.

Table 2. Summary of group differences on sensory screening scores.

	LAT ($n = 30$)	HAT ($n = 17$)	t-Test ($df = 45$)	p	d
Taste	5.23 (2.25)	5.91 (2.39)	−0.97	0.337	0.29
Smell	5.67 (2.31)	7.65 (2.57)	−2.71	0.010	0.82
Vision	5.67 (2.30)	7.18 (2.30)	−2.36	0.022	0.72
Sound	6.13 (2.56)	7.18 (3.15)	−1.24	0.223	0.38
Touch	5.60 (2.34)	6.24 (2.86)	−0.82	0.414	0.25
Texture	5.44 (2.12) $n = 18$	7.31 (2.63) $n = 16$	−2.29	0.029	0.79
Total Without Texture	28.23 (6.98)	35.06 (9.52)	−2.82	0.007	0.86
Total With Texture	32.94 (8.63) $n = 18$	41.5 (10.31) $n = 16$	−2.63	0.013	0.90

Group differences are presented as group means, with standard deviations in parentheses. Abbreviations: low autistic traits group (LAT), high autistic traits group (HAT), degrees of freedom (df).

3.3. Associations with Clinical Variables

A regression analysis was performed using the full sample ($n = 47$) to explore the associations between sensory outcomes and related clinical variables (autistic traits, anxiety, and depression). Analyses suggested that higher autistic traits were associated with heightened sensitivity in the smell modality only (Table 3). Higher depression scores were associated with lower smell sensitivity. No other significant associations were identified.

Table 3. Regression analysis.

	AQ-10 (*B*, *t*, *p*)	HADS Anxiety (*B*, *t*, *p*)	HADS Depression (*B*, *t*, *p*)
Taste	0.17, 1.05, 0.299	−0.03, −0.35, 0.726	−0.08, −0.92, 0.361
Smell	0.43, 2.57, 0.014	0.10, 1.36, 0.181	−0.25, −2.70, 0.010
Vision	0.22, 1.43, 0.161	−0.01, −0.21, 0.838	0.08, 0.96, 0.343
Sound	0.12, 0.59, 0.559	−0.01, −0.08, 0.938	0.02, 0.16, 0.871
Touch	0.04, 0.24, 0.814	0.03, 0.31, 0.760	−0.00, −0.04, 0.966
Texture	0.34, 1.59, 0.123	−0.02, −0.19, 0.854	−0.13, −1.17, 0.251
Total Without texture	1.10, 1.87, 0.069	0.13, 0.49, 0.624	−0.22, −0.69, 0.496
Total With texture	1.48, 1.67, 0.106	0.13, 0.38, 0.704	−0.45, −0.95, 0.349

Abbreviations: low autistic traits group (LAT), high autistic traits group (HAT), Adult Autism Quotient 10 item (AQ-10), Hospital Anxiety and Depression Scale (HADS), regression coefficient (*B*), regression t statistic (*t*), *p*-value (*p*).

3.4. *Evaluation*

Cronbach's Alpha for the scale was 0.72, indicating acceptable internal reliability and that the individual items are measuring the same underlying concept. Across the sample, $n = 9$ (19.15%) of the participants gave feedback on the use of the screener. Feedback was generally positive, including that the form was "clear and easy to follow" and that it gave participants an opportunity to reflect on their sensory experiences. Participants felt that the screener was beneficial in highlighting a need for environmental adaptations:

"It can be very helpful to discover what a particular person likes or dislikes and will help to create an environment comfortable for people who suffer from eating disorders especially during meals."

Negative feedback included changing the formatting and layout of the form to make it clearer, and concerns that only using rating scales did not leave the participants space to fully explore or explain their sensory sensitivities.

4. Discussion

The primary aim of the study was to explore the use and acceptability of a brief, pragmatic sensory screener in a national clinical ED service. This initial pilot study suggests that this screener could potentially be beneficial for use in ED treatment services, with participants generally giving positive feedback and the clinical team finding it helpful to work with this information in the context of treatment. However, further research in larger sample sizes, including an investigation of its psychometric properties, is needed to establish the utility of this screening tool. Potential benefits to this screener identified in this pilot study that could be explored in future research are that it may help both patients and their clinician with awareness, recognition and reflection surrounding sensory difficulties, and their implications for formulation and treatment. The nursing team and dieticians also reported that the tool was quick and easy to administer, and gives useful information that could help make treatment more tailored to individual needs and personalise treatment strategies.

The screener does not provide a detailed exploration of the individual's sensory sensitivities: for example, the single scales for each sensory modality do not capture if someone experiences both hyper- and hyposensitivity in certain situations. Rather, the screener appears to help stimulate thought and discussion around individual sensory needs, and highlights where assessment by an occupational therapist, or using a more detailed sensory measure, could be beneficial. To our knowledge this is the first development of a sensory screening tool specifically for use in ED populations. The piloting of this tool suggests that measures for use in this population could benefit from distinguishing between general sensory sensitivities, and food-specific sensitivities. For example, clinicians and patients recommended that food texture sensitivity be measured independently from general touch/texture sensitivity, and the results indicate that participants did indeed rate themselves differently on these separated modalities.

The secondary aim of the study was to explore whether self-rated sensory sensitivities in AN are related to autistic features, finding that people with AN and high autistic traits scored themselves

as more sensitive in the areas of smell, vision, texture, and overall total screening scores, compared to participants with low autistic traits. This is the first study to explore the relationship between self-rated sensory sensitivity and autistic traits in people with AN, and suggests that autistic traits may contribute to hypersensitivity in this condition [6–9]. The results of this study strongly indicate that future research in this area should consider the potential role of autistic traits in study design and analysis. The finding also supports previous qualitative research in this area suggesting that people with AN and high autistic traits may indeed experience elevated sensory difficulties, and reinforces the possibility that this population may benefit from an assessment of their sensory needs during treatment, and subsequent environmental and dietary adaptations as appropriate [20,22].

However, the nature of the relationship between autistic traits, AN, and sensory sensitivities remains unclear. In the current study, people with AN and high autistic traits had higher scores compared to those with low autistic traits. However, the regression analysis suggested that autistic traits predicted elevated sensitivity in the area of smell only. It is possible that autistic traits impact sensory sensitivity in AN through an additional mediating variable, although a strength of this study is that it controlled for the potential confounders of anxiety and depression in the regression analysis. Two prior studies have explored objective experimental measures of smell sensitivity and autistic traits in AN with conflicting results [28,29]. This reflects evidence from previous neuropsychological research in AN which has found a similar lack of agreement between self-report and experimental measures of cognitive flexibility [30]. It is likely that future research in AN could benefit from using both types of approaches. A key advantage of using self-report measures in clinical settings is that clinicians can more easily carry out subjective reports and use this information to tailor treatment approaches, compared to experimental measures which may need additional resources and expertise. Further research in this area is needed to explore associations between self-reported sensory sensitivity and autistic traits in AN, particularly relation to potential underlying mechanisms. Future research could explore mechanisms hypothesised to influence sensory processing in autism in AN to illuminate the relationship between these areas. In particular, sensory processing in autism has been hypothesised to be related to biased central coherence in this population: autistic people are theorised to exhibit a bias towards detail-orientated information processing as opposed to global processing, or seeing the "bigger picture", which may contribute to hypersensitivity [31]. People with AN also exhibit a bias towards detail-orientated processing which has previously been linked to altered visual processing in this condition [32–35]. Further research on sensory processing and autistic traits in AN could consider this as a potential underlying mechanism.

There are a number of limitations to this study. The nature of this pilot and feasibility study meant that the sample size is relatively small, and future studies could benefit from including a higher number of participants. In particular, the current study did not include a healthy control comparison group. Therefore, it cannot draw conclusions surrounding whether people with AN rate their sensory sensitivity levels differently compared to healthy controls. Findings of hypersensitivity in this study therefore reflect people with AN rating themselves as highly sensitive on the screening measure (against a control marker of "no sensory differences"), rather than people with AN rating themselves as highly sensitive in comparison to people without the condition.

In addition, the current study did not include a full evaluation of the psychometric qualities of the screener, although a preliminary assessment does indicate acceptable internal reliability. The sensory screener was designed as a brief, pragmatic measure for use in clinical practice. It was not designed as a research tool, and therefore the goal of the current study was to explore its use and utility, rather than establishing its reliability and validity, or its agreement with other measures of sensory sensitivity. As the findings of the current study suggest that such a screening tool may be clinically beneficial both to patient and clinicians in ED services, future research could further explore the development and psychometric validation of sensory measures and screening in this population. The development of this sensory screener, in particular separating the modality of touch into a non-food example and a food-based "texture" example, suggests that research on the use and development of sensory screening

in this population should consider whether sensory difficulties in AN are specific to food-related sensations or more generalised. For clinicians, in addition to the use of screening tools a more detailed assessment of sensory difficulties could consider using other tools, such as the Adult Sensory Profile, or the Swedish Eating Assessment for Autism Spectrum Disorders [23,36]. This assessment explores the presence of eating difficulties associated with autism, including items related to sensory sensitivities.

Finally, the present study does present an initial exploration of the relationship between subjective sensory sensitivity and autistic traits within AN populations, but does so in relation to self-rated autistic traits only. The AQ-10 was used in this study to distinguish people with high autistic traits as it is currently recommended for use in healthcare services for this purpose by UK clinical guidelines [37]. However, the AQ-10 and the original 50-item AQ may lack efficacy in distinguishing autism cases in clinical populations [38–41]. In the current study, that the AQ-10 may lack accuracy is suggested by the fact that participants in the HAT group had a lower, albeit non-significant, duration of illness compared the LAT group, whereas characteristics associated with autism assessed with experimental measures are associated with longer illness durations in AN [17]. Future research in this area should consider exploring sensory sensitivity in individuals with AN only compared to people with AN and a diagnosis of autism, or using gold-standard autism measures such as the Autism Diagnostic Observation Schedule (ADOS) known to be effective in this population [42]. In addition, future explorations of sensory sensitivities in AN and autism could benefit from also including a sample group of autistic people without AN.

In conclusion, the findings of the current study indicate the potential utility of using a brief sensory screener to evaluate subjective sensory sensitivity in individuals accessing ED treatment. In addition, the study suggests that subjective hypersensitivity in AN may be related to autistic traits. Implications for future research and potential clinical adaptations are discussed.

Supplementary Materials: The following are available online at http://www.mdpi.com/2077-0383/9/4/1182/s1, Table S1: Brief Sensory Screener.

Author Contributions: Conceptualization, E.K., K.T. and C.P.; formal analysis, E.K.; investigation, Y.D., Z.L., C.P., K.S. and R.A.; data curation, Y.D. and Z.L.; writing—original draft preparation, E.K.; writing—review and editing, E.K., Y.D., K.S. and K.T.; supervision, K.T. and C.S.; project administration, E.K., Y.D., K.S. and K.T.; funding acquisition, K.T. All authors have read and agreed to the published version of the manuscript.

Funding: K.T. was funded by the MRC-MRF Fund, grant number MR/S020381/1, MR/R004595/1; the Health Foundation (an independent charity committed to bring better health care for people in the UK), grant number AIMS ID 1115447. K.T. additionally received support from the Maudsley Charity, an independent NHS mental health charity which works in partnership with patients and families, clinical care teams and researchers at South London and Maudsley NHS Foundation Trust, the Institute of Psychiatry, Psychology and Neuroscience, King's College London, and community organisations, with a common goal of improving mental health, to support innovation, research and service improvement. E.K. was funded by a Medical Research Council Doctoral Training Partnership studentship, grant number MR/N013700/1.

Acknowledgments: The authors would like to thank the clinical teams working in the National Eating Disorder Service (South London and Maudsley NHS Foundation Trust) for their support with this project.

Conflicts of Interest: The authors declare no conflict of interest.

References

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed.; American Psychiatric Publishing: Arlington, VA, USA, 2013.
2. Fichter, M.M.; Quadflieg, N.; Hedlund, S. Twelve-year course and outcome predictors of anorexia nervosa. *Int. J. Eat. Disord.* **2006**, *39*, 87–100. [CrossRef] [PubMed]
3. Gowers, S.G.; Clark, A.; Roberts, C.; Griffiths, A.; Edwards, V.; Bryan, C.; Smethurst, N.; Byford, S.; Barrett, B. Clinical effectiveness of treatments for anorexia nervosa in adolescents: Randomised controlled trial. *Br. J. Psychiatry* **2018**, *191*, 427–435. [CrossRef] [PubMed]
4. Wonderlich, S.; Mitchell, J.E.; Crosby, R.D.; Myers, T.C.; Kadlec, K.; LaHaise, K.; Swan-Kremeier, L.; Dokken, J.; Lange, M.; Dinkel, J.; et al. Minimizing and treating chronicity in the eating disorders: A clinical overview. *Int. J. Eat. Disord.* **2012**, *45*, 467–475. [CrossRef] [PubMed]

5. Riva, G.; Dakanalis, A. Altered Processing and Integration of Multisensory Bodily Representations and Signals in Eating Disorders: A Possible Path Toward the Understanding of Their Underlying Causes. *Front. Hum. Neurosci.* **2018**, *12*, 49. [CrossRef]
6. Bell, K.; Coulthard, H.; Wildbur, D. Self-Disgust within Eating Disordered Groups: Associations with Anxiety, Disgust Sensitivity and Sensory Processing. *Eur. Eat. Disord. Rev. J. Eat. Disord. Assoc.* **2017**, *25*, 373–380. [CrossRef]
7. Brand-Gothelf, A.; Parush, S.; Eitan, Y.; Admoni, S.; Gur, E.; Stein, D. Sensory modulation disorder symptoms in anorexia nervosa and bulimia nervosa: A pilot study. *Int. J. Eat. Disord.* **2016**, *49*, 59–68. [CrossRef]
8. Merwin, R.M.; Moskovich, A.A.; Wagner, H.; Ritschel, L.A.; Craighead, L.W.; Zucker, N.L. Emotion regulation difficulties in anorexia nervosa: Relationship to self-perceived sensory sensitivity. *Cogn. Emot.* **2013**, *27*, 441–452. [CrossRef]
9. Zucker, N.L.; Merwin, R.M.; Bulik, C.M.; Moskovich, A.; Wildes, J.E.; Groh, J. Subjective experience of sensation in anorexia nervosa. *Behav. Res. Ther.* **2013**, *51*, 256–265. [CrossRef]
10. Islam, M.A.; Fagundo, A.B.; Arcelus, J.; Aguera, Z.; Jimenez-Murcia, S.; Fernandez-Real, J.M.; Tinahones, F.J.; de la Torre, R.; Botella, C.; Fruhbeck, G.; et al. Olfaction in eating disorders and abnormal eating behavior: A systematic review. *Front. Psychol.* **2015**, *6*. [CrossRef]
11. Kinnaird, E.; Stewart, C.; Tchanturia, K. Taste sensitivity in anorexia nervosa: A systematic review. *Int. J. Eat. Disord.* **2018**. [CrossRef]
12. Crane, L.; Goddard, L.; Pring, L. Sensory processing in adults with autism spectrum disorders. *Autism* **2009**, *13*, 215–228. [CrossRef]
13. Huke, V.; Turk, J.; Saeidi, S.; Kent, A.; Morgan, J.F. Autism Spectrum Disorders in Eating Disorder Populations: A Systematic Review. *Eur. Eat. Disord. Rev.* **2013**, *21*, 345–351. [CrossRef] [PubMed]
14. Westwood, H.; Mandy, W.; Tchanturia, K. Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Mol. Autism* **2017**, *8*. [CrossRef] [PubMed]
15. Westwood, H.; Mandy, W.; Simic, M.; Tchanturia, K. Assessing ASD in Adolescent Females with Anorexia Nervosa using Clinical and Developmental Measures: A Preliminary Investigation. *J. Abnorm. Child Psychol.* **2017**, *46*, 183–192. [CrossRef] [PubMed]
16. Nazar, B.P.; Peynenburg, V.; Rhind, C.; Hibbs, R.; Schmidt, U.; Gowers, S.; Treasure, J. An examination of the clinical outcomes of adolescents and young adults with broad autism spectrum traits and autism spectrum disorder and anorexia nervosa: A multi-centre study. *Int. J. Eat. Disord.* **2018**, *51*, 174–179. [CrossRef]
17. Saure, E.; Laasonen, M.; Lepisto-Paisley, T.; Mikkola, K.; Algars, M.; Raevuori, A. Characteristics of autism spectrum disorders are associated with longer duration of anorexia nervosa: A systematic review and meta-analysis. *Int. J. Eat. Disord.* **2020**. [CrossRef]
18. Stewart, C.; McElwen, E.S.; Konstantellou, A.; Eisler, I.; Simic, M. Impact of ASD traits on treatment outcomes of eating disorders in girls. *Eur. Eat. Disord. Rev.* **2017**, *25*, 123–128. [CrossRef]
19. Tchanturia, K.; Larsson, E.; Adamson, J. How anorexia nervosa patients with high and low autistic traits respond to group Cognitive Remediation Therapy. *BMC Psychiatry* **2016**, *16*, 334. [CrossRef]
20. Kinnaird, E.; Norton, C.; Stewart, C.; Tchanturia, K. Same behaviours, different reasons: What do patients with co-occurring anorexia and autism want from treatment? *Int. Rev. Psychiatry* **2019**, 1–10. [CrossRef]
21. Kinnaird, E.; Norton, C.; Pimblett, C.; Stewart, C.; Tchanturia, K. Eating as an autistic adult: An exploratory qualitative study. *PLoS ONE* **2019**, *14*, e0221937. [CrossRef]
22. Kinnaird, E.; Norton, C.; Tchanturia, K. Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: A qualitative study. *BMC Psychiatry* **2017**, *17*, 292. [CrossRef] [PubMed]
23. Brown, C.; Tollefson, N.; Dunn, W.; Cromwell, R.; Filion, D. The Adult Sensory Profile: Measuring Patterns of Sensory Processing. *Am. J. Occup. Ther.* **2001**, *55*, 75–82. [CrossRef] [PubMed]
24. Allison, C.; Auyeung, B.; Baron-Cohen, S. Toward Brief "Red Flags" for Autism Screening: The Short Autism Spectrum Quotient and the Short Quantitative Checklist in 1000 Cases and 3000 Controls. *J. Am. Acad. Child Adolesc. Psychiatry* **2012**, *51*, 202–212. [CrossRef] [PubMed]
25. Tchanturia, K.; Smith, E.; Weineck, F.; Fidanboylu, E.; Kern, N.; Treasure, J.; Cohen, S.B. Exploring autistic traits in anorexia: A clinical study. *Mol. Autism* **2013**, *4*. [CrossRef] [PubMed]
26. Westwood, H.; Eisler, I.; Mandy, W.; Leppanen, J.; Treasure, J.; Tchanturia, K. Using the Autism-Spectrum Quotient to Measure Autistic Traits in Anorexia Nervosa: A Systematic Review and Meta-Analysis. *J. Autism Dev. Disord.* **2016**, *46*, 964–977. [CrossRef]

27. Zigmond, A.S.; Snaith, R.P. The Hospital Anxiety and Depression Scale. *Acta Psychiatr. Scand.* **1983**, *67*, 361–370. [CrossRef]
28. Bentz, M.; Guldberg, J.; Vangkilde, S.; Pedersen, T.; Plessen, K.J.; Jepsen, J.R. Heightened Olfactory Sensitivity in Young Females with Recent-Onset Anorexia Nervosa and Recovered Individuals. *PLoS ONE* **2017**, *12*, e0169183. [CrossRef]
29. Tonacci, A.; Calderoni, S.; Billeci, L.; Maestro, S.; Fantozzi, P.; Ciuccoli, F.; Morales, M.A.; Narzisi, A.; Muratori, F. Autistic traits impact on olfactory processing in adolescent girls with Anorexia Nervosa restricting type. *Psychiatry Res.* **2019**, *274*, 20–26. [CrossRef]
30. Lounes, N.; Khan, G.; Tchanturia, K. Assessment of Cognitive Flexibility in Anorexia Nervosa—Self-Report or Experimental Measure? A Brief Report. *J. Int. Neuropsychol. Soc.* **2011**, *17*, 925–928. [CrossRef]
31. Happé, F.; Frith, U. The Weak Coherence Account: Detail-focused Cognitive Style in Autism Spectrum Disorders. *J. Autism Dev. Disord.* **2006**, *36*, 5–25. [CrossRef]
32. Lang, K.; Lopez, C.; Stahl, D.; Tchanturia, K.; Treasure, J. Central coherence in eating disorders: An updated systematic review and meta-analysis. *World J. Biol. Psychiatry* **2014**, *15*, 586–598. [CrossRef] [PubMed]
33. Lang, K.; Roberts, M.; Harrison, A.; Lopez, C.; Goddard, E.; Khondoker, M.; Treasure, J.; Tchanturia, K. Central Coherence in Eating Disorders: A Synthesis of Studies Using the Rey Osterrieth Complex Figure Test. *PLoS ONE* **2016**, *11*, e0165467. [CrossRef] [PubMed]
34. Madsen, S.K.; Bohon, C.; Feusner, J.D. Visual processing in anorexia nervosa and body dysmorphic disorder: Similarities, differences, and future research directions. *J. Psychiatr. Res.* **2013**, *47*, 1483–1491. [CrossRef] [PubMed]
35. Freeman, R.; Touyz, S.; Sara, G.; Rennie, C.; Gordon, E.; Beumont, P. In the eye of the beholder: Processing body shape information in anorexic and bulimic patients. *Int. J. Eat. Disord.* **1991**, *10*, 709–714. [CrossRef]
36. Karlsson, L.; Rastam, M.; Wentz, E. The SWedish Eating Assessment for Autism spectrum disorders (SWEAA)-Validation of a self-report questionnaire targeting eating disturbances within the autism spectrum. *Res. Dev. Disabil.* **2013**, *34*, 2224–2233. [CrossRef]
37. NICE. Autism Spectrum Disorder in Adults: Diagnosis and Management, Clinical Guideline CG142. Available online: https://www.nice.org.uk/guidance/cg142 (accessed on 6 February 2020).
38. Ashwood, K.L.; Gillan, N.; Horder, J.; Hayward, H.; Woodhouse, E.; McEwen, F.S.; Findon, J.; Eklund, H.; Spain, D.; Wilson, C.E.; et al. Predicting the diagnosis of autism in adults using the Autism-Spectrum Quotient (AQ) questionnaire. *Psychol. Med.* **2016**, *46*, 2595–2604. [CrossRef]
39. Baron-Cohen, S.; Wheelwright, S.; Skinner, R.; Martin, J.; Clubley, E. The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J. Autism Dev. Disord.* **2001**, *31*, 5–17. [CrossRef]
40. Sizoo, B.B.; Horwitz, E.H.; Teunisse, J.P.; Kan, C.C.; Vissers, C.; Forceville, E.J.M.; Van Voorst, A.J.P.; Geurts, H.M. Predictive validity of self-report questionnaires in the assessment of autism spectrum disorders in adults. *Autism* **2015**, *19*, 842–849. [CrossRef]
41. Conner, C.M.; Cramer, R.D.; McGonigle, J.J. Examining the Diagnostic Validity of Autism Measures Among Adults in an Outpatient Clinic Sample. *Autism Adulthood* **2019**, *1*, 60–68. [CrossRef]
42. Sedgewick, F.; Kerr-Gaffney, J.; Leppanen, J.; Tchanturia, K. Anorexia Nervosa, Autism, and the ADOS: How Appropriate Is the New Algorithm in Identifying Cases? *Front. Psychiatry* **2019**, *10*, 507. [CrossRef]

Chapter 14: Discussion

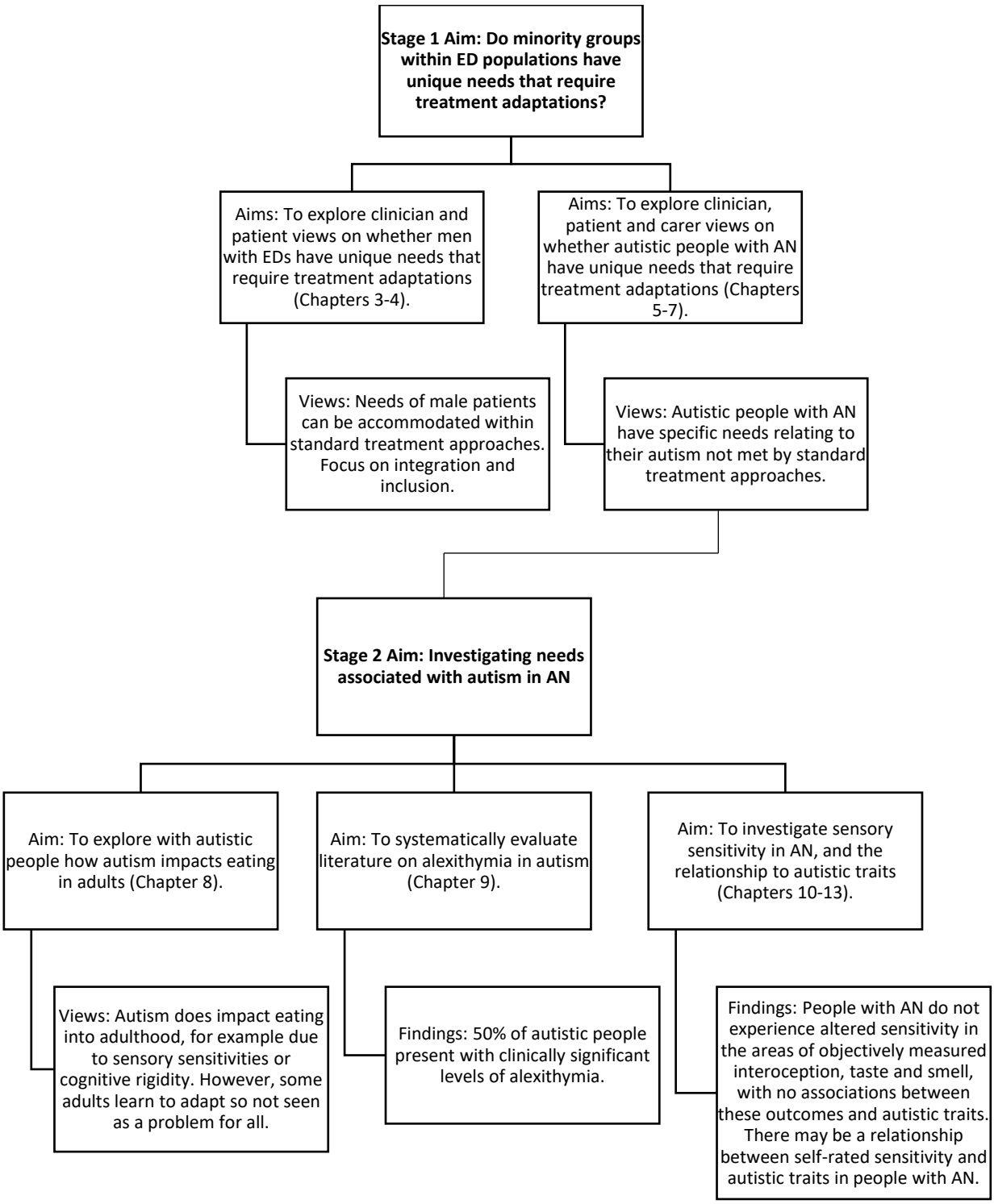
This chapter will synthesise and discuss the findings from the studies presented in the thesis in relation to the wider literature. The overall aim was to explore whether under-recognised minority groups within the wider ED population have unique features that could require treatment adaptations, focusing on two groups: men with EDs, and autistic people with AN. The chapter will begin by discussing the results in relation to these two groups separately (first men with EDs, then autistic people with AN), before giving an overview of the thesis strengths, limitations, and recommendations for future directions.

14.1 Summary of Thesis Aims

The first stage of the thesis aimed to use qualitative methods to explore the views of stakeholders from each group (clinicians, patients and carers) on this topic (Chapters 3-7). The findings of this initial stage suggested that further investigation of features associated with co-occurring anorexia and autism was warranted. The second stage aimed to examine the potentially unique needs of autistic people with AN, including how autism impacts eating in adults (Chapter 8), alexithymia in autism (Chapter 9), and sensory sensitivity in anorexia and autism (Chapters 10-13). The findings of the thesis in relation to these aims are summarised in Figure 1.

Figure 1

Visual Map of Thesis Findings



14.2 Men with Eating Disorders

The thesis aimed to explore the views of clinicians and patients on whether men with EDs have unique needs that require treatment adaptations. This section consists of two qualitative studies: interviews with clinicians with a minimum 3 years of experience working in an ED service (Chapter 3), and interviews with adult male patients with experience of treatment for any ED (Chapter 4). Both studies yielded similar findings: clinicians and patients did not perceive men with EDs as presenting with fundamentally different needs to female patients. There was an emphasis on the importance of treating men as individuals, with gender viewed as just one potentially relevant factor. There was a sense that this individualisation could be achieved through standard, formulation-based approaches to psychological interventions, rather than a need for a separate approach. Rather than necessarily pursuing different treatment approaches for men, the idea of creating a "male-friendly" treatment environment seemed to hold more relevance across both groups.

14.2.1 Treatment Needs

The views and experiences of patients and clinicians explored in Chapters 3-4 suggest that men with EDs do not present with unique needs compared to female patients. That men as a group do not have fundamentally different ED presentations is reflected in previous empirical literature on this topic. This research suggests more similarities than differences in men compared to women, with existing models of ED psychopathology retaining validity in male populations (Bramon-Bosch, Troop & Treasure, 2000; Dakanalis, et al., 2014; Mason & Lewis, 2015; Mitchison & Mond, 2015; Nunez-Navarro, et al, 2012; Perko, et al., 2019).

Rather, there was a perception that men experienced similar treatment needs compared to female patients, but with some differences in presentation. Where differences were identified, these appeared to be closely related to masculine cultural ideals and social roles. For example, both patients and clinicians described how male body image concerns (perceived as focusing around

muscularity) present differently to body image concerns in women (perceived as focusing around thinness). Previous literature suggests that whilst both men and women with EDs experience body image concerns, the actual nature of these concerns varies in line with gendered cultural pressures (Murray, Rieger, Karlov & Touyz, 2013). Traditionally, literature on body image concerns in EDs have focused on the overvaluation and control of weight and shape in relation to thinness in ways which may be less relevant for men (Perko, et al., 2019). Therefore, whilst body image interventions are appropriate for men with EDs, the findings of this thesis and previous research indicate that they require adaptation to include male-specific body image concerns (Andersen, 1990; Kearney-Cooke & Steichen-Asch, 1990; Morgan, 2008).

Clinicians listed more potential differences between men and women with EDs than the male patients themselves. The key difference identified by the male patients was that of body image. By contrast, the clinicians listed a number of other factors they would specifically consider in male patients, including an emphasis on exercise and fitness, perceiving the ED and its treatment in functional, performance-based terms, and difficulty expressing emotions. Whilst clinicians emphasised that these difficulties were not necessarily limited to male patients only, they suggested that in male patients these factors were specifically linked to pressures around cultural masculine ideals. This reflects empirical research suggesting that conformity to masculine ideals may influence male ED presentation, including predicting body image concerns around muscularity (Griffiths, Murray & Touyz, 2015). Significantly, engaging in treatment itself was characterised by clinicians as a potential challenge to patient masculinity. The observations by clinicians on the role of social and cultural pressures around masculinity in treatment for mental health conditions is consistent with previous literature in this area, particularly the concepts that men may respond better to a more functional, performance-based treatment approach, and the importance of challenging or reframing masculine ideals (Emslie, et al., 2007; Syzdek, et al., 2016).

Two features associated with male patients by clinicians were the relevance of exercise, and difficulties around emotion regulation and expression. Previous research suggests that men with EDs may be more likely to engage in compulsive exercise, and that this is tied to emotion regulation (Dakanalis, et al., 2014; Murray, et al., 2014). Research on gender differences in emotion indicates that men are more likely to experience difficulties with emotion recognition compared to women (Baron-Cohen, et al., 1997; Levant, Hall, Williams & Hasan, 2009). In line with the perceptions of clinicians in the present thesis, this has been linked to masculine cultural ideals: the "Normative Male Alexithymia" hypothesis suggests that restricted emotion recognition in men is closely related to societal norms that proscribe the expression of emotion in boys and men (Levant, 1992). Whether this sex difference in emotion regulation extends into ED populations is less clear. There is a lack of experimental-based emotion regulation research investigating differences between men and women with EDs. The findings of separate studies suggest women with AN have greater difficulties with emotion recognition tasks compared to HC women, with women with AN performing at a similar level evidenced in previous studies on HC men (Baron-Cohen, et al., 1997; Harrison, Sullivan, et al., 2010; Russell, et al., 2009). By contrast, men with EDs show no differences in emotion recognition compared to HC men (Goddard, et al., 2013). With evidence from the thesis suggesting that clinicians perceive difficulties in emotion regulation as particularly relevant for male patients, further empirical research in this area could consider directly comparing whether there are objective differences in emotion regulation across male and female patients.

This kind of further empirical investigation could give further insight into whether the ideas raised in these qualitative studies reflect objective differences in men and women with EDs. When triangulating the findings from the clinician and patient interviews, there are some divergences in views between the groups that caution against drawing firm conclusions from this data. For example, it is striking that the clinicians identified more sex differences in ED presentation compared to the male patients. It is possible that the views of clinicians could capture assumptions around male experiences which may not be borne out by experimental exploration. The differences could

also reflect the nature of the insights generated across the two populations: the male patients were discussing their own experiences, and their perspectives as individuals receiving treatment may have limited their ability to comment on sex differences in EDs more generally. By contrast, clinicians approaching the research questions from the perspective of treating multiple patients of different genders may have been better placed to give this kind of comparative overview. Additionally, there was a strong sense in the male patient interviews that they did not want to be treated differently or singled out as men: they may have been motivated to under-report sex differences due to concerns that this would lead to the kinds of separation they were recommending against.

A second divergence across the two studies surrounded the issue of masculinity and its relevance for treatment. Clinicians highlighted this as a key issue, relating potential differences between men and women in ED symptoms and presentation to cultural pressures around masculinity. There was also a suggestion that engaging in ED treatment itself could undermine masculine ideals. However, this issue was not directly addressed by the male patients in their interviews. It should be noted that all the clinicians interviewed were female, and may have been emphasising the importance of masculinity from a theory-based standpoint that potentially had less relevance to the experiences of the male patients. Gender-role adherence varies across individuals and changes over time, with some evidence suggesting that young men are more likely to endorse progressive masculine identities, including greater emotional awareness and willingness to discuss emotional subjects with other men (McCormack & Anderson, 2014; Roberts, 2012). The male patients interviewed were fairly young (mean age 29.43 years), and it would be interesting to explore whether the relevance of masculinity for men with EDs varies with age. In addition, male patients were not directly asked about masculinity (although neither were the clinicians). The thematic analysis style chosen took participant statements at face value with a realist approach: a more interpretative, discursive analysis style might have focused on the suggestion of implicit masculine ideals in the participants' language. Adapting this approach from the beginning of the thesis could have also led to a more exploratory interview style investigating masculine identities in relation to ED treatment.

14.2.2 Implications for Treatment

An overview of recommended treatment adaptations for men with EDs derived from the qualitative studies is given in Table 1, including a summary of whether each adaptation was mentioned across both groups. It should be emphasised that participants not mentioning a particular adaptation does not mean that the group actively advocated against the idea: it only reflects that participants did not raise it as a possibility.

Table 1

Summary of male ED treatment recommendations, including whether adaptation was mentioned in findings for each group.

Treatment recommendation	Clinicians	Patients
Focus on individual, not on gender	Yes	Yes
More work around emotion recognition and regulation	Yes	Not raised
Addressing physical differences	Yes	Not raised
Challenging traditional ideas of masculinity	Yes	Not raised
Addressing stigma of male EDs	Yes	Not raised
Inclusive treatment environment	Yes	Yes
Changing treatment materials to include	Yes	Yes

male examples/ experiences		
Making ward decorations less female-centric	Yes	Yes
Male-only groups	Not consistently endorsed	Not consistently endorsed
Male clinicians for male patients	Not consistently endorsed	Not consistently endorsed

Whilst the recommendations for a male-friendly treatment space reflect previous research on male EDs, the current study gives greater insight into male patient perspectives on what this might look like in practice (Robinson, et al., 2012). In contrast to previous clinical recommendations there was no clear desire for segregated, male-specific treatment provision, particularly on the part of male patients (Dearden & Mulgrew, 2012; Weltzin, et al., 2012). For example, outside of the ED field, mental health treatments have been developed specifically for men which explicitly address the role of masculine norms (Primack, Addis, Syzdek & Miller, 2010; Robertson & Williams, 2010; Syzdek, et al., 2014). However, centring gender in treatment in this way, and providing different interventions for men, contrasts with the perspectives of male patients in the thesis who did not feel that separate treatment approaches were necessary and perceived this explicit focus on gender as potentially exclusionary and stigmatising. Rather, there was an emphasis on the inclusion of men into existing treatment approaches and spaces, such as integrating examples of male patients throughout standard materials rather than providing separate materials or book chapters for men.

One area that was raised by the clinicians, but not the patients, was that of addressing and treating physical problems in men. EDs are associated with physical complications, but whether these manifest differently in men is under-researched. There is some indication that BMIs may be more

difficult to interpret as indicators of risk in men: one study found that whilst men admitted to an ED treatment programme had relatively high BMIs, the percentage of body weight reported as lost during the illness was consistent with severe malnutrition (Vo, Lau & Rubinstein, 2016). Moreover, patients were found to present with cardiac complications, with more than half of patients meeting criteria for hospitalization. Men with AN may also be at higher risk of osteoporosis and elevated liver enzymes (Mehler, et al, 2008; Nagata, et al., 2015). This could reflect the possibility that men are less likely to seek treatment, and so do not present for assessment until their ED reaches a severe stage (Raisanen & Hunt, 2014). Alternatively, it could indicate that men with EDs are at risk of becoming medically unstable more quickly than women. The findings of the current thesis support wider calls for clear guidelines for clinicians concerning the medical assessment of men with EDs, particularly whether standard markers of risk vary in this population compared to women (Ganson, Murray & Nagata, 2019).

Therefore, Chapters 3 and 4 exploring treatment adaptations for men with EDs indicated that different treatment approaches may not be necessary for this population. Rather, men could benefit from standard treatment approaches delivered by clinicians sensitive to potential features associated with male EDs, within an inclusive treatment environment. By contrast, Chapters 5-7 exploring stakeholder views on treatment adaptations for autistic people with AN suggested more fundamental problems.

14.3 Autistic People with Anorexia Nervosa

The thesis initially aimed to explore the views of clinicians and patients on whether autistic people with AN have unique needs that require treatment adaptations using a qualitative approach (Chapters 5 and 6). Following findings from the clinician and patient interviews indicating that this area warranted further research, this exploratory stage was extended to include carers (Chapter 7). The triangulated results indicated that autistic people with AN have specific needs that may not be met by standard treatment approaches, sometimes resulting in deteriorating relationships with

services and distress on the part of patients and carers. Clinicians reported a lack of confidence in treating this population, and highlighted that systematic guidelines for adapting interventions for autistic people with AN do not exist. Therefore, subsequent studies were carried out to further investigate specific domains perceived as impacting treatment. Chapter 8 explored how autism continues to affect eating in adults in ways that may not be accounted for in previous primarily child-based literature, and Chapter 9 used a systematic review and meta-analysis to demonstrate a heightened prevalence of alexithymia in autism compared to non-autistic controls. The main focus of this second stage was on sensory sensitivities in AN and autism: whilst stakeholders highlighted the importance of addressing sensory differences in treatment, this area is under-explored in previous experimental research. Following a systematic review synthesising the literature on taste in AN (Chapter 10), Chapters 11 and 12 assessed whether autistic traits are associated with three sensory modalities in AN: taste, smell and interoception. These studies identified no differences between people with AN and HC in experimental measures of sensory sensitivity, and no correlations between sensory outcomes and autistic traits within the AN group. Finally, the potential clinical translation of recommendations by stakeholders that sensory differences should be addressed in treatment was explored through the development and piloting of a brief sensory screening questionnaire in an ED service (Chapter 13). This study did identify a relationship between self-reported sensory sensitivity and autistic traits, indicating that this area could benefit from further research.

14.3.1 Treatment Needs

In the qualitative studies exploring the views of clinicians, patients and carers (Chapters 5-7), there was a strong sense that autistic people with AN have specific or different treatment needs that are not being met by standard approaches. These treatment needs are summarised in Table 2, together with whether they were endorsed across the different groups. Again, that a particular need was not

mentioned by a group does not mean that the group actively denied that the need exists; only that it was not raised by participants.

Table 2

Needs associated with co-occurring autism and AN highlighted during stakeholder qualitative studies.

Need	Clinicians	Patients	Carers
Differing communication styles	Yes	Yes	Yes
Difficulties with emotion recognition/ expression	Yes	Yes	Not raised
Cognitive rigidity/ routinic behaviour	Yes	Yes	Yes
Sensory problems	Yes	Yes	Yes
Social difficulties	Not raised	Yes	Yes
Executive functioning problems	Not raised	Yes	Not raised

Findings across the three groups regarding treatment needs experienced by autistic people were fairly consistent. The only major point of disagreement surrounded the characterisation of problems with communication. Clinicians identified problems as originating in the communicative styles of the patients: for example, describing autistic patients as "curt" or characterising them as speaking a different language. This is in line with traditional perceptions of communication difficulties associated with autism which characterise problems as arising from "deficits" on the part of the autistic person (as in current DSM diagnostic criteria; APA, 2013). By contrast, patients located the source of communication difficulties in the clinicians themselves, perceiving clinicians as not

listening to their views. Carers similarly voiced frustrations around services not listening to their concerns, and this appeared to be linked to ED service clinicians lacking the training or experience in working with autistic people with AN. This breakdown in communication between clinicians and patients could reflect the "double empathy problem". Rather than attributing communication difficulties between neurotypical and autistic people to deficits associated with autism, this theory suggests that disconnects in communication arise from a bi-directional mismatch in communicative styles, reciprocity and mutual understanding (Milton, 2012). For example, autistic people are known to find it difficult to read the minds of others, but neurotypical people also have difficulties in reading the minds and interpreting the behaviour of autistic people (Edey, et al., 2016; Sheppard, et al., 2016). In the context of this previous literature, the findings of the current thesis suggest a need for clinician training and support in communicating with autistic people. With the stakeholder qualitative studies describing breakdowns in the therapeutic alliance, a more collaborative, reflective, and communicative approach could help with building positive relationships in this population.

These qualitative chapters highlighted a number of treatment needs in this population. However, are these needs actually unique to autistic people with AN, compared to their non-autistic peers? With the exception of sensory problems, the different needs highlighted in the interviews and summarised in the table are hypothesised to be key developmental and maintaining factors in the cognitive-interpersonal model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). For example, as part of the second stage of the thesis, the prevalence of difficulties with emotion recognition in autism were further investigated using a systematic review and meta-analysis of studies using a self-report measure of alexithymia (Chapter 9). This suggested that around 50% of autistic people experience clinically significant levels of alexithymia, reinforcing the views of stakeholders in the qualitative studies which suggested that autistic people with AN may require additional support around emotion recognition in treatment. However, difficulties with emotion recognition are not unique to autism: alexithymia is also known to be heightened in AN, with

previous studies using the same measure finding similar prevalence rates (Eizaguirre, et al., 2004; Montebarocci, et al., 2006; Westwood, Kerr-Gaffney, et al., 2017). In the cognitive-interpersonal model of AN, alexithymia is related to difficulties perceiving and understanding the self that are thought to contribute to the development and maintenance of the disorder.

In the qualitative stakeholder studies there was a perception across participant groups that autistic people with AN do present with specific needs that are not experienced by their non-autistic peers. The suggestion that these needs are somehow different in autism and AN could to an extent be an artifact of the interview style, with questions to all stakeholders asking participants to reflect on differences associated with co-occurring autism and AN. However, a recurring concept in the interview studies was that autistic people with AN on the surface experience similar behaviours to people with AN only, but that the underlying motivations or mechanisms are different. Therefore, it is possible that people with AN only and autistic people with AN experience similar difficulties, but with variations in presentations or underlying mechanisms. This requires further research. One possibility highlighted in the qualitative studies is that these difficulties may have a different longitudinal trajectory for autistic people. Autism is a lifelong condition and therefore its core cognitive features are theorised to present across the lifespan, although adaptive or compensatory processes may alter behavioural presentations (Gotham, Pickles & Lord, 2012; Pugliese, et al., 2016; Rosenthal, et al., 2013). Therefore, difficulties (for example, with cognitive rigidity) may be present prior to the onset of AN for an autistic person, and persist following recovery. In line with this, recent research has found that autistic social traits in childhood predate and are associated with disordered eating during teenage years (Solmi, et al., 2020). However, whether these features are less stable in AN compared to autistic people is unclear: neuropsychological characteristics associated with autism in AN have been similarly found to exist prior to illness onset, and to persist following recovery (Harrison, Tchanturia & Treasure, 2010; Holliday, et al., 2005; Roberts, Tchanturia & Treasure, 2013; Saure, et al., 2020; Tenconi, et al., 2010).

Another possibility is that approaching autism in AN from the perspective of unique needs was misguided. There is disagreement in the literature around whether autism should be described dimensionally, or as a distinct category, or using an approach that combines features of both systems (for example, defining thresholds within dimensions; Lord & Jones, 2012). A dimensional perspective may be particularly appropriate for understanding autism in AN: autistic traits are known to be elevated in AN populations, including in the absence of an underlying autism condition (Westwood, Mandy, Simic & Tchanturia, 2017). Therefore, it is possible that autistic people with AN do experience similar difficulties to people with AN only, but that perceived differences arise because these are experienced at a higher level of severity. Empirical research has found that people with AN and autistic people exhibit similar theory of mind profiles, but that these difficulties are heightened in autistic people (Leppanen, et al., 2018). Similarly, Westwood, Mandy & Tchanturia (2017a & 2017b) demonstrated that autism in AN is associated with increased alexithymia and cognitive rigidity. Further research is needed to explore this relationship, particularly from a longitudinal perspective which could help give insight into whether there is a difference in the long-term presentation of these difficulties in autistic people with AN compared to people with AN only.

Since the publication of these qualitative studies, a new paper investigating the relationship between autism and AN using similar methods has been published (Brede, et al., 2020). This uses interviews with stakeholders to hypothesise a model of autism-specific mechanisms underlying restrictive EDs in autistic women. The model reflects similar themes identified in the current thesis research, including the salience of sensory difficulties, emotion regulation, social difficulties and cognitive rigidity, and the concept of AN itself acting as a coping mechanism for these problems. It goes further in exploring the underlying processes that link these difficulties to the development of restrictive eating problems, including how food restriction may help numb and/or resolve emotional dysregulation and sensory problems. However, further research is needed to illuminate how far these mechanisms are autism-specific, implying a potential need for different treatment approaches, as opposed to general risk factors for AN.

14.3.2 Sensory Sensitivity

A key need associated with autism highlighted in the qualitative studies as impacting treatment for AN was that of sensory difficulties. Sensory difficulties are under-explored in relation to AN and autistic traits. For example, unlike the other needs raised in the thesis, external sensory difficulties are not discussed as a factor in the cognitive-interpersonal model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Interoceptive difficulties are raised in the cognitive-interpersonal model as potentially contributing to the core maintaining and developmental factor of "difficulties understanding the self", but discussed primarily in relation to embodiment and associated proprioceptive processes, rather than the narrower definition of interoception as relating to the perception of internal physiological signals (Craig, 2002; Eshkevari, et al., 2012). Therefore, the second stage of the thesis primarily focused on further investigating the relationship between sensory sensitivity and autistic traits in AN. The thesis operationalised sensory sensitivity as an individual's ability to detect and identify sensory stimuli.

14.3.2.1 Experimental findings. In the experimental research in Chapters 11-12 no objective differences in interoceptive, taste and smell sensitivity in people with AN compared to HC were identified. With previous literature suggesting bottom-up alterations in sensory sensitivity in autism, this could suggest that these differences are specific to autism, not AN, and that sensory difficulties therefore represent a unique need for autistic people with AN (Robertson & Baron-Cohen, 2017). The evidence is weakest for interoception: the heartbeat tracking task is increasingly discredited as a measure of interoceptive accuracy, and interoceptive differences have not been reliably documented in autistic populations (Brener & Ring, 2016; Desmedt, Luminet & Corneile, 2018; Nicholson, et al., 2018). However, the taste and smell measures are well-validated, and research in the autism field does suggest objective differences in sensitivity in these modalities. Only a small number of studies have examined taste in autism, and suggest that autism is associated with lowered sensitivity (Bennetto & Kuschner, 2007; Damiano, et al., 2014; Tavassoli & Baron-Cohen,

2012). More studies have examined smell in autism with inconsistent findings (Boudjarane, et al., 2017). A meta-analysis suggests that autistic people do experience objective olfactory differences, but not only in one direction: their findings indicate that autism is associated with both hypo- and hypersensitivity (Larsson, Tirado & Wiens, 2017).

That objective taste and smell sensitivity could represent a difference between autistic people and people with AN only, with implications for the needs experienced by autistic people with AN, is further supported by the thesis finding that no relationship between these objective measures and self-reported autistic traits (using the AQ) was identified within the AN population. By contrast, research on the other needs raised in the qualitative research (communication and social difficulties, cognitive rigidity and alexithymia) have identified associations between these features and autistic traits in AN populations (Anckarsater, et al., 2012; Kerr-Gaffney, Harrison & Tchanturia, 2020; Hobson, et al., 2020; Westwood, Mandy & Tchanturia, 2017a, Westwood, Mandy & Tchanturia, 2017b). The lack of relationship between autistic traits and sensory sensitivity identified in current experimental studies could reflect a methodological issue, with concerns that the AQ may not be an accurate measure of autistic traits in clinical populations (Sizoo, et al., 2015). However, it should be noted that a previous study on olfaction and autistic traits in AN using a more reliable measure (the ADOS) similarly found no relationship (Bentz, Guldberg, et al., 2017a).

Therefore, the potential for objective taste and smell sensitivity to represent a unique feature in autistic people with AN warrants further investigation. The findings of this thesis in relation to previous taste and smell research in autism are suggestive of a difference, but this interpretation is speculative and limited in a number of ways. Firstly, directly comparing the current findings to this previous research is difficult due to variations in populations sampled. Research on taste and smell in AN (including the current thesis) is predominantly based on majority female samples, and previous research in autism has the opposite sex bias (systematic review of taste research in Chapter 10; Boudjarane, et al., 2017; Islam, et al., 2015;). Wider research suggests that women perform

better than men on olfaction measures (Sorokowski, et al., 2019). Therefore, future research comparing matched samples of people with AN, autistic people, and autistic people with AN are required to further unpack whether sensory sensitivity is truly a unique need in co-occurring autism and AN.

Secondly, it should be noted that whilst the current thesis found no evidence for objective differences in taste and smell in people with AN, previous findings in this area have been mixed and inconsistent (Chapter 10; Islam, et al., 2015). However, a newly published meta-analysis supports the findings of the current thesis in olfaction, finding no differences between people with AN and HC (Mai, et al., 2020). The paper did find that clinical features in AN moderated smell sensitivity, but not in a consistent direction: higher BMI was associated with higher smell sensitivity, and higher ED severity was associated with lower smell sensitivity. State factors such as BMI and treatment status have also been linked with taste sensitivity in AN in previous research (Aschenbrenner, et al., 2008). This could indicate that smell and taste differences in AN represent a state which varies with illness severity, rather than a trait, in contrast to evidence that sensory differences in autism are a core phenotypic trait (Robertson & Baron-Cohen, 2017).

14.3.2.2 Self-report findings. The experimental findings that there were no objective differences between people with AN and HC on sensory measures contrasts with previous self-report research and the findings of a self-report measure developed for this thesis. Self-report literature on AN consistently suggests that people with AN experience hypersensitivity to external sensations, and hyposensitivity to interoceptive sensations (Bell, et al., 2017; Brand-Gofelth, et al., 2016; Jenkinson, et al., 2018; Merwin, et al., 2013; Zucker, et al., 2013). This could suggest a divergence between subjective and objective measures of sensation in AN. Significantly, this difference could also be reflected in the relationship of these assessments to autistic traits: in the current thesis, self-reported hypersensitivity was related to autistic traits in people with AN as measured by a novel screening questionnaire.

It is likely that this divergence in findings reflects the possibility that self-report assessments of sensory difficulties assess different constructs to experimental measures, in particular top-down processes that influence sensory perception. Top-down processes theorised to alter sensory sensitivity with relevance to both AN and autism include differences in attentional modulation, weak central coherence (resulting in heightened attention to detail and difficulties with integration), and altered reward or hedonic processing (Oberndorfer, et al., 2013; Robertson & Baron-Cohen, 2017). Self-report assessments may capture these influences, whereas the experimental findings measured the bottom-up detection and identification of stimuli only. For example, three out of the four previous self-report studies finding hypersensitivity in AN used the Adolescent/Adult Sensory Profile (AASP; Bell, et al., 2017; Brown & Dunn, 2002; Merwin, et al., 2013; Zucker, et al., 2013). The AASP does not only measure the detection of sensory stimuli, but includes items that measure attention and affective reactions to sensory stimuli. The brief screening questionnaire developed and evaluated in this thesis similarly used rating prompts that reflect hedonic and behavioural reactivity to stimuli, such as references to enjoyment and avoidance. By contrast, the current thesis found no differences in self-reported taste and smell sensitivity in people with AN as measured by the SPQ, which was specifically designed to measure basic sensory function only in the absence of attentional or affective influences (Tavassoli, Hoekstra & Baron-Cohen, 2014). Therefore, it is possible that self-report assessments of sensory difficulties may be assessing different sensory constructs to experimental measures, specifically elements of sensory reactivity or responsiveness (Schulz & Stephenson, 2020). Sensory reactivity is also known to be altered in autism, but is under-explored in AN as a distinct construct (Tavassoli, et al., 2016).

Future research should consider further exploring top-down sensory processes in AN, and influences on sensory reactivity, and the relationship to autistic traits using experimental measures to better isolate these constructs. One interpretation of this divergence between self-reported sensitivity and experimental measures in AN, and wider research in autism, is that sensory difficulties in people with AN only may be driven by top-down aspects, in contrast to autistic people who exhibit

differences in their bottom-up ability to detect and identify sensory stimuli. This would have implications for understanding sensory sensitivity in autistic people with AN, who may experience unique bottom-up difficulties compared to their non-autistic peers with implications for treatment. However, at this stage this is speculative and requires more research.

14.3.2.3 Implications for maintenance models of AN. The findings of this thesis on sensory sensitivity have implications for maintenance models of AN, both in relation to people with AN only, and for the application of these models in autistic people with AN. Understanding alterations in taste and smell sensitivity in AN, and co-occurring autism, is important as potential sensory differences are relevant to neurobiological maintenance models of AN. These posit that atypical taste sensitivity could contribute to appetite dysregulation through alterations in sensory, reward and hedonic pathways (Frank, et al., 2013; Kaye, Fudge & Paulus, 2009; Kaye, et al., 2011; Kaye, et al., 2013). In the model first proposed by Kaye and co-authors (2009), the enduring dietary restriction characteristic of AN is thought to reflect altered brain circuitry involved in regulating appetite and eating behaviour. Gustatory processing circuitry in the brain is responsible for integrating the reward, hedonic and sensory aspects of eating (Rolls, 2007; Small, 2006). As highlighted in a recent systematic review (Kot, et al., 2019), brain imaging studies examining responses to sweet taste stimuli in AN have demonstrated alterations in gustatory processing areas (Frank, et al., 2013; Oberndorfer, et al, 2013; Wagner, et al., 2008). Establishing whether sensitivity to food stimuli is altered in AN, such as in the taste and smell domains, is important as it gives insight into the hypothesised underlying causes of altered neural responses seen in these studies. The findings of no differences in sweet taste sensitivity in this thesis suggest that these alterations observed in previous brain imaging research reflect top-down reward and hedonic responses to taste stimuli, or how the stimulus is encoded in the brain, rather than differences in sensory identification of the stimuli itself (Frank, et al., 2013; Frank, et al., 2016; Olsavsky, et al., 2019). This is in line with the reward-centred maintenance model of AN which posits the centrality of altered higher-order reward processes, particularly in the appraisal of food and taste stimuli (O'Hara, Campbell & Schmidt, 2015). In this

model, aversive appraisal of taste stimuli is theorised to be driven by the perception of food restriction and weight loss as rewarding and a consequent cognitive aversion to weight gain, rather than by differences in sensory perception of the stimuli itself.

However, if bottom-up sensitivity is additionally altered specifically in autistic people with AN, but not people with AN only, then this could create variations in this circuitry independent of reward and hedonic assessments (Rolls, 2007). Therefore, further investigation of this area is necessary to establish whether altered taste sensitivity represents a specific biological vulnerability contributing to AN maintenance in autistic people. Furthermore, altered interoception in the form of satiety signalling is also implicated in this circuitry (Rolls, 2007). With controversy surrounding the use of the heartbeat tracking task, and a lack of clarity in the research literature on whether interoception is altered in AN and autistic populations, future research specifically investigating interoceptive sensitivity relating to satiety could further illuminate the role of neurobiological factors in both people with AN only, and autistic people with AN (Brener & Ring, 2016; Desmedt, Luminet & Corneile, 2018; Nicholson, et al., 2018).

Additionally, the potential divergence between perceived and actual sensory experiences in AN warrants further investigation as they could be relevant to the interpersonal-cognitive model of AN, specifically the “difficulties understanding the self” factor (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Previous research has considered how altered proprioceptive and visuotactile sensory information may contribute to altered perception in relation to embodiment and body image, but the current findings suggest that there could be wider difficulties with the processing and experience of sensory information (Eshkevari, et al., 2012). These differences could also be interrelated to other aspects of understanding the self implicated in AN: gaps between subjective and objective sensory perception have been linked in previous research to altered bodily representations in AN, and difficulties with emotion recognition in other populations (Garfinkel, et al., 2016; Khalsa, Hassanpour, et al., 2018). Further research into how people with AN experience

their bodies and related sensory sensations could give greater insight into disturbed bodily experience as a developmental and maintenance factor in this condition.

14.3.3 Implications for Treatment

An overview of recommended treatment adaptations for autistic people with AN derived from the qualitative stakeholder interviews is provided in Table 3. Similarly to the findings in male EDs, there was an emphasis on the importance of an individualised, flexible approach. In contrast, there was a sense that this individualised approach should be based around needs primarily arising from the co-occurring autism, whereas in the male ED findings gender was viewed as just one of a number of relevant factors.

Whether or not autistic people with AN experience unique treatment needs is highly relevant to the issue of treatment adaptations. One of the key reasons for developing adaptations to CBT interventions for autistic people experiencing mental health problems like anxiety and depression is that autistic people have additional cognitive or social difficulties compared to non-autistic people with the same conditions (Cooper, Loades & Russell, 2018). Approaching treatments specifically for autism and AN may therefore be different to previous research on treatment adaptations for autism, as both conditions are associated with similar socio-cognitive profiles. Some of the treatment recommendations highlighted in the present study reflect techniques and approaches already used in AN, including addressing emotional difficulties and cognitive rigidity (Schmidt & Treasure, 2006; Tchanturia, Lounes & Holttum, 2014; Tchanturia, Doris, Mountford & Fleming, 2015; Treasure & Schmidt, 2013). If difficulties in co-occurring autism and AN are not unique, and also occur in AN only, then this may be positive for the clinical implementation of treatments for this population. Treatments that already exist for AN, particularly those that target socio-emotional and cognitive difficulties, may be appropriate with minor adaptations for co-occurring autism and AN, and adaptations for autistic people with AN may also benefit individuals with AN only. For example, CRT for AN (targeting cognitive rigidity and central coherence difficulties) has been demonstrated to

increase cognitive flexibility in people with AN and high autistic traits at similar levels to those with low autistic traits, as long as it is delivered on an individual rather than a group basis (Dandil & Smith, et al., 2020; Tchanturia, Larsson & Adamson, 2016).

Table 3

Summary of treatment recommendations for autistic people with AN, including whether adaptation was mentioned in findings for each group.

Treatment recommendation	Clinicians	Patients	Carers
Individualised/ flexible approach	Yes	Yes	Yes
Training for clinicians	Yes	Yes	Yes
Recognising and formulating role of autism in AN	Yes	Yes	Yes
Recognising the potential role of masking difficulties	Not raised	Yes	Yes
Addressing difficulties with emotion recognition	Yes	Yes	Not raised
Addressing difficulties with thought identification	Yes	Not raised	Not raised
Addressing cognitive rigidity	Yes	Yes	Not raised

Adapting communication (for example, writing things down)	Yes	Yes	Yes
Addressing sensory difficulties	Yes	Yes	Yes
Use of worksheets/ practical prompts	Yes	Not raised	Not raised
Involving family members in therapy	Yes	Not raised	Not raised
Support for carers	Not raised	Not raised	Yes
Maintaining a routine with appointments	Yes	Not raised	
More time in treatment	Not raised	Yes	Not raised
Support with executive functioning problems	Not raised	Yes	Not raised
Referral for diagnosis where autism is suspected but not confirmed	Yes	Yes	Yes

One area raised by the stakeholder interviews in Chapters 5-7, and further explored in the second stage of the thesis in Chapter 9, was the need to address difficulties with emotion recognition in treatment. A systematic review and meta-analysis demonstrated that emotion recognition problems are indeed heightened in autistic people compared to controls, and that around 50% of autistic people present with clinically significant levels of alexithymia. Alexithymia is also known to be

heightened in AN, and has been linked to poorer treatment outcomes and a need for more intensive and lengthy interventions (Iancu, Cohen, Ben Yehuda & Kotler, 2006; Speranza, Loas, Guilbaud & Corcos, 2011; Westwood, Kerr-Gaffney, et al., 2017). Previous research demonstrating that alexithymia is associated with heightened autistic traits in AN indicates that addressing difficulties with emotion recognition may be particularly relevant for autistic people with AN (Westwood, Mandy & Tchanturia, 2017a). This population may therefore benefit from interventions that specifically target emotion recognition problems. Heightened autistic traits have not been found to impact responses to combined cognitive remediation and emotion skills training (CREST) for AN, indicating its potential efficacy for autistic people with AN (Adamson, et al., 2018).

These treatment recommendations are similar to previous research on adapting CBT interventions for autistic people, but do also raise a number of issues that may be more specific to treating autistic people with AN (Lang, et al., 2010; Spain, et al., 2015; Walters, et al., 2016). For example, previous work on CBT interventions for autistic people have explored adaptations for populations already diagnosed with autism, whereas a specific difficulty working in the ED field is that patients may not have an autism diagnosis (Mandy & Tchanturia, 2015). Therefore, clinicians have the additional role of recognising that someone may be autistic and referring for treatment, and may require further training and support in this area.

Another previously under-explored area which may have particular relevance for treating autistic people with AN is that of adaptations for sensory difficulties. Previous research on CBT adaptations for autistic people have primarily addressed sensory sensitivity in relation to environmental adaptations (Spain & Happe, 2020). Understanding sensory difficulties may be particularly relevant in treating AN due to the nutritional rehabilitation aspect of treatment: if an autistic person with AN has sensory sensitivities surrounding food, this could impact their ability to adhere to a standard diet plan. Whilst the experimental studies in this thesis suggest that more research is needed to unpack this area, the qualitative findings highlight the salience of sensory difficulties in the presentation and

treatment of autistic people with AN. In line with these recommendations, this thesis developed and trialled a brief sensory screening questionnaire for people with AN. Although the measure requires further evaluation, feedback from participants suggested that using this kind of brief assessment may be beneficial for both clinicians and patients in exploring sensory difficulties and informing treatment.

One aspect of treating autistic people with AN raised in this thesis were perceptions of change and recovery. All stakeholder groups raised this issue, highlighting that for autistic people difficulties relevant for treatment (such as social difficulties, cognitive rigidity, or sensory sensitivity) represent traits rather than states relating to the onset of the ED. Therefore, these difficulties may have preceded their ED, and would likely persist following recovery. This distinction was viewed as impacting treatment: clinicians suggested that they might explore adapting around autistic traits rather than aiming for fundamental changes, and patients highlighted that recovering from an ED may involve accepting some remaining rigidity around food and related behaviours. This concept of change versus adaptation around eating difficulties in autistic people was further explored in a qualitative study examining how autism impacts eating in adults. With previous research on autism and eating focusing on child studies, this paper raised a number of aspects of autism that contribute to eating behaviours in adulthood (Bandini, et al., 2010; Cermak, Curtin & Bandini, 2010; Nadon, et al., 2011). Whilst most of these factors (difficulties with social eating, a preference for routines, sensory difficulties) had been raised in the qualitative research on treating autism and AN, the paper gave a novel insight into processes of change. The experiences of autistic adults suggested that whilst these core differences exist across their lifespan, it is possible to learn to cope and adapt around difficulties so that they are no longer perceived as problematic or inhibiting. The findings of this qualitative research specifically in the area of eating behaviours reflects wider empirical research documenting the importance of adaptive processes in improving functional outcomes in autistic adults (Pugliese, et al., 2016). To further understand treatment needs and illness outcomes in this population, future research could explore similarities and differences in the recovery process

for autistic people with AN compared to people with AN only. In particular, the concept of adaptation versus change has implications for treatment approaches, and clinician, patient and carer expectations about treatment and its goals.

Overall, this thesis raises a number of needs associated with co-occurring autism and AN which may require different approaches or adaptations by clinicians in treatment. Across the stakeholder interviews, a clear link was made between clinician knowledge and training in autism and EDs, and better patient and carer experiences of treatment. This reflects both NICE guidelines and the latest Autism Act strategy, both of which emphasise that clinicians working with autistic people should have training and supervision around the needs of this population (Department of Health, 2015a; HM Government, 2014; NICE CG142, 2016). With an increasing body of research documenting the needs of autistic people with AN, the development of guidelines, training and support for clinicians working in the ED field could help translate this work into clinical practice.

Further research could also consider exploring whether certain treatment approaches for AN may be more or less beneficial for autistic people with the condition. As previously noted, the needs and treatment recommendations for autistic people are similar to a number of interventions which already target these modalities. MANTRA, and lower intensity interventions such as CRT, specifically address aspects including cognitive rigidity, difficulties with emotion recognition, and social problems, whilst focusing to a lesser extent on shape and weight concerns (Schmidt & Treasure, 2006; Tchanturia, et al., 2014; Tchanturia, et al., 2015; Treasure & Schmidt, 2013). By contrast, the possibility raised in the current thesis and more recent research that body image concerns may be less salient for autistic people with AN could have implications for the transdiagnostic model of EDs and CBT-E, which both emphasise the role of weight and shape concerns in ED maintenance and development (Brede, et al., 2020; Fairburn, et al., 2003). Whilst the literature on autism and AN indicates that the cognitive-interpersonal model has validity in this population, it would be interesting to explore the applicability of the transdiagnostic CBT model of EDs for autistic people.

The low sample sizes of the stakeholder studies meant that the thesis was not able to explore perspectives and experiences regarding individual interventions, but this could be addressed by future research.

14.4 Differences Between Groups

The thesis focused on two specific groups, men with EDs, and autistic people with AN, that had previously been identified in the research literature as at risk of experiencing poorer treatment experiences and outcomes. The studies in this thesis did not directly compare the two groups, limiting its ability to make comparisons. However, the concerns of the two groups differ in ways that may give further insight into the experiences of these populations in ED treatment. The qualitative interviews with stakeholders suggested that, whilst men wanted an emphasis on their individuality over their gender, in the co-occurring autism and AN patient and carer interviews there was a strong impression that participants wanted their autistic identities and needs to be recognised as different and prioritised. In short, men with EDs experienced not fitting in, and autistic people with AN experienced not standing out.

For men, this concern about not fitting in may be linked to pressures associated with their identities specifically as men with EDs, rather than their identities as men. Outside of ED services men are not a minority or marginalised group and feelings of stigma may primarily relate to the temporary, specific experience of having an ED. For men, accessing ED treatment may heighten this feeling of difference and stigmatisation, leading male patients to prioritise integration. By contrast, for autistic people, experiences of stigma and difference relating to their autistic identities are more typical, and perhaps unlikely to be especially activated just by accessing ED services (Bargiela, et al., 2016; Portway & Johnson, 2005). This enduring experience of difference may make autistic people less likely to prioritise lessening this feeling of atypicality, and more likely to emphasise the importance of having their needs recognised. This recalls a previous study that found that a fear of labelling and

stigma relating to an autism diagnosis was a barrier to seeking healthcare for only a minority of autistic adults (Vogan, et al., 2017).

The priority of recognition for autistic people may also reflect the sometimes-invisible nature of autism as an identity status. In the absence of other factors such as gender dysphoria or an intersex condition, someone's identity as a cisgender man is a fact known to both themselves and likely apparent to the people around them. As a group category, autism is more difficult to identify, and has been described as an "invisible disability". There is no biomarker or objective test: an autism diagnosis is based on assessments that require interpretation and clinical judgement that may not be attuned to female presentations (Kreiser & White, 2014; Mandy, et al., 2012). When autistic women enter ED services, their autism may not have been recognised or diagnosed (Mandy & Tchanturia, 2015). Alternatively, even when a diagnosis has been made, the experiences of patients and carers in the current thesis highlight that their identity and needs as an autistic person may still not be acknowledged due to a lack of clinician training. For men whose identity as a minority within ED services is obvious, recognition is unlikely to be a priority compared to integration. The findings of this thesis suggest that autistic people may have the opposite problem, with both their identity and needs going unrecognised.

14.5 Future Directions

The thesis highlights a number of recommendations for future research into men with EDs and autistic people with AN, that may also be relevant for future work on treating minority groups within ED populations more widely. Specific suggestions for further research are outlined in each individual chapter. The purpose of this section is to give a broad overview of possible future directions for this area.

The findings of the thesis suggest that men with EDs and autistic people with AN do experience treatment differently as minority groups, and that this needs to be considered both in individual formulation and in the wider treatment environment. However, some of the needs associated with

these groups require further research in order to inform appropriate approaches in treatment. For example, investigating differences between autistic people and people with AN could inform whether specific treatment approaches are needed for people with both of these conditions. In particular, further research into sensory difficulties in autism and AN is required to illuminate implications for illness maintenance and treatment needs in autistic people with AN. Whilst the current thesis focused only on sensory sensitivity relating to the ability to detect sensory stimuli, further research could also consider investigating other aspects of sensory processing known to be altered in autism, such as sensory reactivity or difficulties integrating multiple or complex sensory inputs (Ostrolenk, et al., 2019; Tavassoli, et al., 2016).

A key factor informing treatment experiences emphasised in the qualitative studies across both groups was the importance of clinician experience and training. Interviews with clinicians suggested that their confidence in working with both groups was closely related to their prior experience and knowledge of working with these populations. Similarly, autistic patients and carers with positive treatment experiences cited clinician expertise in working with autistic people as a key factor in this process. Therefore, future work should consider the development of guidelines on working with these groups. This is particularly important for the treatment of autistic people with AN, with clinicians generally reporting lower confidence in working with what they perceived to be "difficult" cases. NICE guidelines and government strategy dictate that autistic people should be offered adapted mental health interventions delivered by trained clinicians: the findings of this thesis indicate that more work is required in this area to achieve this in the ED field (Department of Health, 2015a; HM Government, 2014; NICE CG142, 2016).

However, the stakeholder interviews suggest that ensuring individual clinicians are competent in treating individuals from these groups may not be enough to ensure positive treatment experiences. For the male ED group in particular, patients did not report difficulties with their individual treatment delivered by clinicians, but rather felt that feelings of exclusion arose in the wider

treatment environment. Co-occurring autism and AN stakeholder interviews similarly highlighted the importance of adapting the treatment environment, particularly considering sensory aspects that might inhibit their ability to engage in treatment. Therefore, future clinical work in this area should consider both individual clinician expertise, but also the accessibility of the wider environment.

Overall, the thesis suggests a number of different treatment recommendations and adaptations for both men with EDs and autistic people with AN. Further research would benefit from empirically evaluating the implementation of specialised treatment approaches and adaptations for these populations. The findings also indicate directions for future research beyond these specific groups. The present thesis investigated the treatment experiences and needs of autistic people with AN only. Further research could investigate how far these experiences and related recommendations are relevant to autistic people with other EDs. In particular, the presentation of autistic people with AN has been linked in recent research to ARFID, a condition also thought to be associated with a heightened prevalence of autism (Brede, et al., 2020; Nicely, et al., 2014).

14.6 Thesis Strengths

A strength of the current thesis was its use of qualitative research to foreground patient, clinician and carer experiences and views, and basing its experimental aims and hypotheses on priorities identified by these stakeholders. This reflects understandings of gold-standard evidence-based practice informing ED treatment as based in a combination of research evidence, clinician experience, and patient views (Peterson, et al., 2016).

Secondly, this thesis includes the first studies to explore the treatment experiences of autistic people with AN, giving insights not only into potential factors behind poor treatment outcomes in this population, but also the relationship between autism and AN. It also includes some of the first research to investigate the relationship between sensory sensitivity and autism in AN. By investigating these novel areas, the thesis highlights a number of areas that can now be explored by further research.

14.7 Thesis Limitations

One limitation of the thesis is that its findings are primarily relevant to the two minority groups of men with EDs and autistic people with AN, rather than minorities within ED populations more widely. The thesis only focused on these two groups, and so cannot comment on adaptations for other minority populations. Furthermore, the thesis did not consider the potential aspect of intersecting minority identities. For example, it did not consider how male experiences of ED treatment might be impacted if they also identify as gay, despite research suggesting that gay men may be at higher risk of developing EDs (Boisvert & Harrell, 2009; Bramon-Bosch, et al., 2000; Carlat, et al., 1997).

In particular, an obvious oversight of the thesis is that it did not consider autistic men with EDs: although this was not an exclusion criterion, all patients participating in the co-occurring autism and AN interviews identified as female or non-binary, and all carers were parents of daughters. Therefore, the thesis inadvertently excluded the perspectives of men whilst investigating autism and AN, despite arguing in its male-focused sections that men are excluded from ED research with negative implications. This is important in the context of research suggesting that the female dominant ED gender ratio may be less skewed in autistic populations, and suggestions that autistic men and women may present differently (Karjalainen, et al., 2016; Kreiser & White, 2014). Consequently, it should be noted that the qualitative exploration of co-occurring autism and AN does not capture the experiences and needs of autistic men. The exclusion of male perspectives from this thesis reflects concerns that research on autism and AN may not reflect wider autism populations. Although the majority of autistic people are men, research in this area has exclusively used female-only, or majority-female samples (Loomes, Hull & Mandy, 2017; Westwood & Tchanturia, 2017). In addition, around half of autistic people may have a co-occurring learning disability (Emerson & Baines, 2010). However, people with learning disabilities are under-represented in ED research, and there are concerns that existing understandings of EDs, and

associated treatments, may lack applicability in these populations (Gravestock, 2003; Thomas; 1994). For example, learning disabilities may be associated with additional difficulties around food not typically seen in AN, including pica, and difficulties with physical coordination, chewing and swallowing (Gravestock, 2003). Co-occurring learning disabilities were not considered in the present thesis: for example, participants in the qualitative studies were not asked if they, or their daughter, had a learning disability. Finally, the nature of the studies in this thesis- participating in interviews, attending a research centre to participate in an interactive sensory testing session- may have also excluded autistic people with more profound communication or anxiety difficulties, although steps were taken in the interview designs to address this limitation (for example, allowing autistic participants to choose whether to be interviewed in person, over the phone, or over instant messenger, and providing interview questions ahead of time). Therefore, there is a strong risk that both the current thesis and wider research on AN and autism reflects the experiences of a small section of autistic people, and that its findings lack generalisability to wider autistic populations. Future research should consider addressing this limitation by exploring EDs, and eating difficulties in more representative samples of autistic people.

An additional limitation of the thesis was that the sample sizes for the stakeholder qualitative studies were fairly small, and recruited the majority of participants from London-based ED services. This is a particular drawback for Chapters 3 & 5 interviewing clinicians, which represent small sample sizes taken from a single ED service. The small and specific sample reflects the fact that these clinician interviews were designed as pilot studies intended to explore the area of treatment adaptations for these minority groups, and to inform the development of interview schedules for future interviews with patients and carers. However, this also limited the range of perspectives engaged in these studies. In particular, the majority of clinicians interviewed about treatment adaptations for autistic people with AN reported that they lacked experience and confidence working with this population. Whilst this raises the important possibility that clinicians working in the ED field may require additional training and support in working with autistic people, it restricted

the paper's ability to explore what kinds of treatment adaptations may be most beneficial. Further research could consider exploring the views of clinicians more experienced in working with co-occurring autism and EDs, and including participants from a wider range of ED services and geographical locations.

Finally, the thesis was limited in its ability to explore whether these two groups experience unique needs, including in its experimental stage exploring sensory sensitivity in AN and autism. Despite initial designs aiming to compare autistic people with AN to people with AN only, difficulties in recruiting enough people with AN meeting clinical criteria for autism meant that the final analyses compared people with AN to HC, measuring autistic traits as a continuous variable using a self-report measure. Additionally, the studies did not include a control group of autistic people without AN. Therefore, the thesis could not assess whether sensory sensitivity does represent a unique need for autistic people with AN, compared to people with AN only.

14.8 Conclusions

This thesis focused on men with EDs, and autistic people with AN. Studies explored whether these groups have unique needs that require treatment adaptations. The findings of studies interviewing clinicians and men with experience of ED treatment indicated that there may not be a need for fundamentally different treatment approaches, but that treatments should be individualised and delivered in an inclusive environment. By contrast, studies interviewing clinicians, carers, and autistic people with experience of treatment for AN suggested a high level of unmet needs, poor treatment experiences, and a lack of clinician confidence or support in treating this population.

The thesis then further explored needs associated with autism that may impact AN treatment. This included investigating how autism impacts eating in adults, and potential adaptive and coping strategies that could help address eating difficulties in this population. The thesis also further explored the contention that autistic people with AN may need additional support in treatment around emotion recognition by carrying out a systematic review and meta-analysis of alexithymia in

autistic people, demonstrating that up to 50% of autistic people experience clinically significant levels of alexithymia.

The final part of the thesis focused on empirically exploring sensory difficulties in AN and the relationship to autistic traits. Findings suggested that people with AN do not experience objective differences in taste, smell, and interoceptive sensory sensitivity, and did not identify any relationship with autistic traits. This has implications for neurobiological understandings of AN that require further research. Reflecting the perceived importance by stakeholders of recognising sensory problems when treating autistic people with AN, a brief sensory screening questionnaire was developed and piloted. In contrast to the experimental findings, this found that people with AN and high autistic traits did exhibit hypersensitivity compared to people with AN and low autistic traits. Further studies are needed to further explore sensory difficulties in autism and AN, particularly differences and similarities between autistic people with AN, and their non-autistic peers.

References

Adamson, J., Leppanen, J., Murin, M. & Tchanturia, K. (2018). Effectiveness of emotional skills training for patients with anorexia nervosa with autistic symptoms in group and individual format. *European Eating Disorders Review, 26*(4), 367-375. doi:0.1002/erv.2594

Adamson, J. & Kinnaird, E., Glennon, D., Oakley, M., & Tchanturia, K. (2020). Carers' views on autism and eating disorders comorbidity: qualitative study. *BJPsych Open, 6*(3), e51. doi:10.1192/bjo.2020.36

Addis, M.E. (1997). Evaluating the Treatment Manual as a Means of Disseminating Empirically Validated Psychotherapies. *Clinical Psychology, 4*(1), 1-11. doi:10.1111/j.1468-2850.1997.tb00094.x

Adler, N.E. & Rehkopf, D.H. (2008). U.S. Disparities in Health: Descriptions, Causes, and Mechanisms. *Annual Review of Public Health, 29*, 235-252. doi:10.1146/annurev.publhealth.29.020907.090852

Agras, W.S., Schneider, J.A., Arnow, B., Raeburn, S.D. & Telch, C.F. (1989). Cognitive-behavioural and response-prevention treatments for bulimia nervosa. *Journal of Consulting Clinical Psychology, 57*(2), 215-21. doi:10.1037//0022-006x.57.2.215

Agras, A.W., Telch, C.F., Arnow, B., Eldregde, K., Wilfley, D.E., Raeburn, S.D., Henderson, J. & Marnell, M. (1994). Weight loss, cognitive-behavioral, and desipramine treatments in binge eating disorder. An additive design. *Behaviour Therapy, 25*(2), 225-237. doi:10.1016/S0005-7894(05)80285-0

Agras, W.S., Walsh, T., Fairburn, C.G., Wilson, G.T. & Kraemer, H.C. (2000). A multicenter comparison of cognitive-behavioral therapy and interpersonal psychotherapy for bulimia nervosa. *Archives of General Psychiatry, 57*(5), 459-66. doi:10.1001/archpsyc.57.5.459

Agras, W.S., Lock, J., Brandt, H., Bryson, S.W., Dodge, E., Halmi, K.A., Jo, B., Johnson, C., Kaye, W., Wilfley, D. & Woodside, B. (2014). Comparison of 2 family therapies for adolescent anorexia nervosa: a randomized parallel trial. *JAMA Psychiatry, 71*(11), 1279–1286. doi:10.1001/jamapsychiatry.2014.1025

Aguera, Z., Sanchez, I., Granero, R. Riesco, N., Steward, T., Martin-Romera, V., Jimenez-Murcia, S., Romero, X., Caroleo, M., Segura-Garcia, C., Menchon, J.M. & Fernandez-Aranda, F. (2017). Short-Term Treatment Outcomes and Dropout Risk in Men and Women with Eating Disorders. *European Eating Disorders Review, 25*(4), 293-301. doi:10.1002/erv.2519

Aguera, Z., Paslakis, G., Munguía, L., Sánchez, I., Granero, R., Sánchez-González, J., Steward, T., Jimenez-Murcia, S. & Fernandez-Aranda, F. (2019). Gender-Related Patterns of Emotion Regulation

among Patients with Eating Disorders. *Journal of Clinical Medicine*, *8*(2), 161. doi:10.3390/jcm8020161

Alfonsson, S., Parling, T. & Ghaderi, A. (2015). Group behavioral activation for patients with severe obesity and binge eating disorder: a randomized controlled trial. *Behavior Modification, 39*(2), 270-294. doi:10.1177/0145445514553093

Ali, K., Farrer, L., Fassnacht, D.B., Gulliver, A., Bauer, S. & Griffiths, K.M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. *International Journal of Eating Disorders, 50*, 9-21. doi:10.1002/eat.22598

Allen, R., Davis, R. & Hill E. (2013). The Effects of Autism and Alexithymia on Physiological and Verbal Responsiveness to Music. *Journal of Autism and Developmental Disorders, 43*, 432-444. doi:10.1007/s10803-012-1587-8

Allison, C., Auyeung, B. & Baron-Cohen, S. (2012). Toward Brief "Red Flags" for Autism Screening: The Short Autism Spectrum Quotient and the Short Quantitative Checklist in 1,000 Cases and 3,000 Controls. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(2), 202-212. doi:10.1016/j.jaac.2011.11.003

Ambrosecchia, M. Ardizzi, M., Russo, E., Ditaranto, F., Speciale, M., Vinai, P., Todisco, P., Maustro, S. & Gallese, V. (2017). Interoception and Autonomic Correlates during Social Interactions. Implications for Anorexia Nervosa. *Frontiers in Human Neuroscience, 11*(219). doi:10.3389/fnhum.2017.00219.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Arlington, VA. doi:10.1176/appi.books.9780890423349

American Psychiatric Association (2010). *Publication manual of the American Psychological Association* (6th ed.). Arlington, VA.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA. doi:10.1176/appi.books.9780890425596

American Psychiatric Association (2020). *Publication manual of the American Psychological Association* (7th ed.). Arlington, VA.

Anckarsater, H., Hofvander, B., Billstedt, E., Gillberg, I. C., Gillberg, C., Wentz, E. & Rastam, M. (2012). The sociocommunicative deficit subgroup in anorexia nervosa: autism spectrum disorders and neurocognition in a community-based, longitudinal study. *Psychological Medicine, 42*, 1957-1967. doi:10.1017/S0033291711002881

Andersen, A.E. (1990). Diagnosis and Treatment of Males with Eating Disorders. In Andersen, A.E. (Ed.), *Males with Eating Disorders* (pp. 100-115). Brunner/Mazel.

Arcaya, M.C., Arcaya, A.L., & Subramanian, S.V. (2015). Inequalities in health: definitions, concepts, and theories. *Global Health Action, 8*, 27106. doi:10.3402/gha.v8.27106

Arcelus, J., Mitchell, A.J., Wales, J. & Nielsen, S. (2011). Mortality Rates in Patients With Anorexia Nervosa and Other Eating Disorders: A Meta-analysis of 36 Studies. *Archives of General Psychiatry, 68*(7), 724-731. doi:10.1001/archgenpsychiatry.2011.74

Arellano, D., Rauh, R., Krautheim, B., Spicker, M., Schaller, U.M., Helzle, V. & Deussen, O. (2018). Interactive testbed for research in autism—the SARA project. *Universal Access in the Information Society, 17*, 21036. doi:10.1007/s10209-016-0521-9

Arnow, K.D., Feldman, T., Fichtel, E., Hsiao-Jung Lin, I., Egan, A., Lock, J., Westerman, M. & Darcy, A.M. (2017). A qualitative analysis of male eating disorder symptoms. *Eating Disorders, 25*(4), 297-309. doi:10.1080/10640266.2017.1308729

Asaria, M., Doran, T. & Cookson, R. The costs of inequality: whole-population modelling study of lifetime inpatient hospital costs in the English National Health Service by level of neighbourhood deprivation. *Journal of Epidemiology & Community Health, 70*, 990-996. doi:10.1136/jech-2016-207447

Aschenbrenner, K., Scholze, N., Joraschky, P. & Hummel, T. (2008). Gustatory and olfactory sensitivity in patients with anorexia and bulimia in the course of treatment. *Journal of Psychiatric Research, 43*(2), 129-137. doi:10.1016/j.jpsychires.2008.03.003

Ashwin, C., Chapman, E., Howells, J., Rhydderch, D., Walker, I. & Baron-Cohen, S. (2014). Enhanced olfactory sensitivity in autism spectrum conditions. *Molecular Autism, 53*. doi:10.1186/2040-2392-5-53

Ashwood, K.L., Gillan, N., Horder, J., Hayward, H., Woodhouse, E., McEwen, F.S., Findon, J., Eklund, H., Spain, D., Wilson, C.E., Cadman, T., Young, S., Stoencheva, V., Murphy, C.M., Robertson, D., Charman, T., Bolton, P., Glaser, K., Asherson, P., Simnoff, E. & Murphy, D.G. (2016). Predicting the diagnosis of autism in adults using the Autism-Spectrum Quotient (AQ) questionnaire. *Psychological Medicine, 46*(12), 2595-2604. doi:10.1017/S0033291716001082

Atalayer, D., Gibson, C., Konopacka, A., & Geliebter, A. (2013). Ghrelin and eating disorders. *Progress in Neuro-Psychopharmacology & Biological Psychiatry, 40*, 70–82. doi:10.1016/j.pnpbp.2012.08. 011

Austen, E. & Griffiths, S. (2019). Why do men stigmatize individuals with eating disorders more than women? Experimental evidence that sex differences in conformity to gender norms, not biological sex, drive eating disorders' stigmatization. *Eating Disorders, 27*(3), 267-290. doi: 10.1080/10640266.2018.1499337

Autism Act (2009). Retrieved from http://www.legislation.gov.uk/ukpga/2009/15/section/3

Baer, R.A., Smith, G.T., Hopkins, J., Krietemeyer, J. & Toney, L. (2006). Using Self-Report Assessment Methods to Explore Facets of Mindfulness. *Assessment, 13*(1), 27-45. doi:10.1177/1073191105283504

Bagby, R. M., Parker, J. D. A. & Taylor, G. J. (1994) The twenty-item Toronto Alexithymia Scale-I. Item selection and cross-validation of the factor structure. *Journal of Psychosomatic Research, 38*(1), 23-32. doi:10.1016/0022-3999(94)90005-1

Bailer, U., de Zwann, M., Leisch, F., Strand, A., Lennkh-Wolfsberg, C., El-Giamal, N., Hornik, K. & Kasper, S. (2004). Guided self-help versus cognitive-behavioral group therapy in the treatment of bulimia nervosa. *International Journal of Eating Disorders, 35*(4), 522-537. doi10.1002/eat.20003

Banasiak, S. J., Paxton S. J., Hay, P. (2005). Guided self-help for bulimia nervosa in primary care: a randomized controlled trial. *Psychological Medicine, 35*(9), 1283-1294. doi:10.1017/S0033291705004769

Bandini, L. G., Anderson, S. E., Curtin, C., Cermak, S., Evans, E. W., Scampini, R., Maslin, M. & Must, A. (2010). Food Selectivity in Children with Autism Spectrum Disorders and Typically Developing Children. *The Journal of Pediatrics, 157*(2), 259-264. doi:10.1016/j.jpeds.2010.02.013

Bargiela, S., Steward, R., & Mandy, W. (2016). The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental disorders*, *46*(10), 3281–3294. doi:10.1007/s10803-016-2872-8

Barnes, J.L., Lombardo, M.V., Wheelwright, S., Baron-Cohen, S. (2009). Moral Dilemmas Film Task: a study of spontaneous narratives by individuals with autism spectrum conditions. *Autism Research, 2*(3), 148-156. doi:10.1002/aur.79

Barnhill, K., Gutierrez, A., Ghossainy, M., Marediya, Z., Devlin, M., Sachdev, P., Marti, N. & Hewitson, L. (2018). Dietary status and nutrient intake of children with autism spectrum disorder: A case-control study. *Research in Autism Spectrum Disorders, 50*, 51-59. doi:10.1016/j.rasd.2018.03.002

Baron-Cohen, S., Jolliffe, T., Mortimore, C. & Robertson, M. (1997). Another Advanced Test of Theory of Mind: Evidence from Very High Functioning Adults with Autism or Asperger Syndrome. *Journal of Child Psychology and Psychiatry, 38*(7), 813-822. doi:10.1111/j.1469-7610.1997.tb01599.x

Baron-Cohen, S., Wheelwright, S., Skinner, S., Martin, J. & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): evidence from asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*(1), 5-17. doi:10.1023/a:1005653411471

Baron-Cohen, S., Jaffa, T., Davies, S., Auyeung, B., Allison, C. & Wheelwright, S. (2013) Do girls with anorexia nervosa have elevated autistic traits? *Molecular Autism, 4*. doi:10.1186/2040-2392-4-24

Baron-Cohen, S. (2017). Neurodiversity – a revolutionary concept for autism and psychiatry. *Journal of Child Psychology and Psychiatry, 58*(6), doi:10.1111/jcpp.12703

Bauer, S., Okon, E., Meermann, R. & Kordy, H. (2012). Technology-enhanced maintenance of treatment gains in eating disorders: efficacy of an intervention delivered via text messaging. *Journal of Consulting and Clinical Psychology, 80*(4), 700-706. doi:10.1037/a0028030

Beck, A.T., Ward, C.H., Mendelsn, M., Mock, J. & Erbaugh, J. (1961). An Inventory for Measuring Depression. *Archives of General Psychiatry, 4*(6), 561-571. doi:10.1001/archpsyc.1961.01710120031004

Becker, A. E., Franko, D. K., Speck, A. & Herzog, DB. (2003). Ethnicity and differential access to care for eating disorder symptoms. *International Journal of Eating Disorders, 33*(2), 205-12. doi:10.1002/eat.10129

Begeer, S., Koot, H.M., Rieffe, C., Meerum Terwogt, M. & Stegge, H. (2008). Emotional competence in children with autism: Diagnostic criteria and empirical evidence. *Developmental Review, 28*(3), 342-369. doi:10.1016/j.dr.2007.09.001

Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F. & Koot, H.M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(5), 1151–1156. doi:10.1007/s10803-012-1656-z

Beighley, J.S., Matson, J.L., Rieske, R.D. & Adams, H.L. (2013). Food selectivity in children with and without an autism spectrum disorder: Investigation of diagnosis and age. *Research in Developmental Disabilities, 34*(10), 3497-3503. doi:10.1016/j.ridd.2013.07.026

Bell, K., Coulthard, H., Wildbur, D. (2017). Self-Disgust within Eating Disordered Groups: Associations with Anxiety, Disgust Sensitivity and Sensory Processing. *European Eating Disorders Review, 25*(5), 373-380. doi:10.1002/erv.2529

Bennetto, L., Kuschner, E. S., & Hyman, S. L. (2007). Olfaction and taste processing in autism. *Biological Psychiatry*, *62*(9), 1015–1021. doi:10.1016/j.biopsych.2007.04.019

Ben-Sasson, A., Hen, L., Fluss, R., Cermak, S.A., Engel-Yeger, B. & Gal, E. (2009). A Meta-Analysis of Sensory Modulation Symptoms in Individuals with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 39*(1), 1-11. doi:10.1007/s10803-008-0593-3

Bentz, M., Guldberg, J., Vangkilde, S., Pedersen, T., Plessen, K.J. & Jepsen, J.R. (2017). Heightened Olfactory Sensitivity in Young Females with Recent-Onset Anorexia Nervosa and Recovered Individuals. *PloS One*, *12*(1), e0169183. doi:10.1371/journal.pone.0169183

Bentz, M., Jepsen, J.R.M., Pedersen, T., Bulik, C.M., Pedersen, L., Pagsberg, A.K. & Plessen, K.J. (2017). Impairment of social function in young females with recent-onset anorexia nervosa and recovered individuals. *Journal of Adolescent Health, 60*(1), 23-32. doi:1016/j.jadohealth.2016.08.011.

Beresnevaite, M. (2000). Exploring the Benefits of Group Psychotherapy in Reducing Alexithymia in Coronary Heart Disease Patients: A Preliminary Study. *Psychotherapy and Psychosomatics, 69*(3), 117-122. doi:10.1159/000012378

Berling, K., Knutsson, J., Rosenblad, A., & von Unge, M. (2011). Evaluation of electrogustometry and the filter paper disc method for taste assessment. *Acta Oto-Laryngologica, 131*(5), 488–493. doi:10.3109/00016489.2010.535850

Berthoz, S. & Hill, E.L. (2005). The validity of using self-reports to assess emotion regulation abilities in adults with autism spectrum disorder. *European Psychiatry, 20*(3), 291-298. doi:10.1016/j.eurpsy.2004.06.013

Berthoz, S., Lalanne, C., Crane, L. & Hill, E.L. (2013). Investigating Emotional Impairments in Adults With Autism Spectrum Disorders and the Broader Autism Phenotype. *Psychiatry Research, 208*(3), 257-264. doi:10.1016/j.psychres.2013.05.014

Bertino, M., Beauchamp, G., & Engelman, K. (1982). Long-term reduction in dietary sodium alters the taste of salt. *American Journal of Clinical Nutrition, 36*(6), 1134–1144.

Bird, G., Silani, G., Brindley, R., White, S., Frith, U. & Singer, T. (2010). Empathic brain responses in insula are modulated by levels of alexithymia but not autism. *Brain, 133*(5), 1515-1525. doi: 10.1093/brain/awq060

Bird, G. & Cook, R. (2013). Mixed emotions: the contribution of alexithymia to the emotional symptoms of autism. *Translational Psychiatry, 3*, e285. doi:10.1038/tp.2013.61

Bjelland, I., Dahl, A. A., Haugg, T. T. & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of Psychosomatic Research, 52*(2), 69-77. doi:10.1016/s0022-3999(01)00296-3

Boesveldt, S., & de Graaf, K. (2017). The differential role of smell and taste for eating behavior. *Perception, 46*(3–4), 307–319. doi:10.1177/0301006616685576

Boisvert, J. A. & Harrell, A. (2009). Homosexuality as a risk factor for eating disorder symptomatology in men. *The Journal of Men's Studies, 17*(3), 210-225. doi:10.3149/jms.1703.210.

Bora, E. & Kose, Sezen. (2016). Meta-analysis of Theory of Mind in Anorexia Nervosa and Bulimia Nervosa: A Specific İmpairment of Cognitive Perspective Taking in Anorexia Nervosa? *International Journal of Eating Disorders, 49*(8), 739-740. doi:10.1002/eat.22572

Boudjarane, M., Grandgeorge, M., Marianowski, R., Misery, L. & Lemonnier, E. (2017). Perception of odors and tastes in autism spectrum disorders: A systematic review of assessments. *Autism Research, 10*(6), 1045-1057. doi:10.1002/aur.1760

Boyce, J.M., & Shone, G.R. (2006). Effects of ageing on smell and taste. *Postgraduate Medical Journal*, *82*(966), 239–241. doi:10.1136/pgmj.2005.039453

Bramon-Bosch, E., Troop, N. A. & Treasure, J. L. (2000). Eating disorders in males: a comparison with female patients. *European Eating Disorders Review, 8*(4), 321-328. doi: 10.1002/1099-0968(200008)8:4<321::AID-ERV355>3.0.CO;2-G

Brand-Gothelf, A., Parush, S., Eitan, Y., Admoni, S., Guar, E. & Stein, D. (2016). Sensory modulation disorder symptoms in anorexia nervosa and bulimia nervosa: A pilot study. *International Journal of Eating Disorders, 49*, 59-68. doi:10.1002/eat.22460

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

Brede, J., Babb, C., Jones, C., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Fox, J. & Mandy, W. (2020). "For Me, the Anorexia is Just a Symptom, and the Cause is the Autism": Investigating Restrictive Eating Disorders in Autistic Women. *Journal of Autism and Developmental Disorders.* doi:10.1007/s10803-020-04479-3.

Brener, J. & Ring, C. (2016). Towards a psychophysics of interoceptive processes: the measurement of heartbeat detection. *Philosophical transactions of the Royal Society of London. Series B, Biological Sciences*, *371*(1708), 20160015. doi:10.1098/rstb.2016.0015

Brett, D., Warnell, F., McConachie, H., & Parr, J. R. (2016). Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014. *Journal of Autism and Developmental Disorders*, *46*(6), 1974–1984. doi:10.1007/s10803-016-2716-6

Brewer, R., Happe, F., Cook, R. & Bird, G. (2015). Commentary on "Autism, oxytocin and interoception": Alexithymia, not Autism Spectrum Disorders, is the consequence of interoceptive failure. *Neuroscience & Biobehavioral Reviews, 56*, 348-353. doi:10.1016/j.neubiorev.2015.07.006

Brewer, R., Cook, R. & Bird, G. (2016). Alexithymia: a general deficit of interoception. *Royal Society Open Science, 3*(10). doi:10.1098/rsos.150664

Brooks, S.J., Barker, G.J., O'Daly, O.G., Brammer, M., Williams, S.C., Benedict, C., Schiöth, H.B., Treasure, J., & Campbell, I.C. (2011). Restraint of appetite and reduced regional brain volumes in anorexia nervosa: a voxel-based morphometric study. *BMC Psychiatry*, *11*, 179. doi:10.1186/1471-244X-11-179

Brown, C. & Dunn, W. (2002). *Adolescent/Adult Sensory Profile*. San Antonio: Pearson Education.

Bruch, H. (1962). Perceptual and conceptual disturbances in Anorexia Nervosa. *Psychosomatic Medicine, 24*, 187-94. doi:10.1097/00006842-196203000-00009.

Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J., & Stein, N. (2012). Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. *Journal of Autism and Developmental Disorders, 42*(11), 2498–2504. doi:10.1007/s10803-012-1496-x

Brugha, T.S., Spiers, N. Bankart, J., Cooper, S.A., McManus, S., Scott, F.J., Smith, J. & Tyrer, F. (2016). Epidemiology of Autism in Adults Across Age Groups and Ability Levels. *The British Journal of Psychiatry, 209*(6), 498-503. doi:10.1192/bjp.bp.115.174649

Bryant-Waugh, R. (2019). Feeding and Eating Disorders in Children. *Psychiatric Clinics of North America, 42*(1), 157-167. doi: 10.1016/j.psc.2018.10.005

Buhren, K., Schwarte, R., Fluck, F., Timmesfield, N., Krei, M., Egberts, K., Pfeiffer, E., Fleischhaker, C., Wewetzer, C. & Herpetz-Dahlmann, B. (2014). Comorbid Psychiatric Disorders in Female Adolescents With First-Onset Anorexia Nervosa. *European Eating Disorders Review, 22*(1), 39-44. doi:10.1002/erv.2254

Bulik, C. M., Sullivan, P. F., Joyce, P. R., Carter, F. A. & McIntosh, V. V. (1998). Predictors of 1-year treatment outcome in bulimia nervosa. *Comprehensive Psychiatry, 39*(4), 206-2014. doi:10.1016/s0010-440x(98)90062-1

Buron, E. & Bulbena, A. (2013). Olfaction in Affective and Anxiety Disorders: A Review of the Literature. *Psychopathology, 46*(2), 63-74. doi:10.1159/000338717

Button, E., Aldridge, S. & Palmer, R. (2008). Males assessed by a specialized adult eating disorders service: Patterns over time and comparisons with females. *International Journal of Eating Disorders, 41*(8), 758-61. doi:10.1002/eat.20553

Caglar-Nazali, H.P., Corfield, F., Cardi, V., Ambawni, S., Leppanen, J., Olabintan, O., Deriziotis, S., Hadjimichalis, A., Scognamiglio, P., Eshkevari, E., Micali, N. & Treasure, J. (2014). A Systematic Review and Meta-Analysis of 'Systems for Social Processes' in Eating Disorders. *Neuroscience and Behavioural Reviews, 42*, 55-92. doi:10.1016/j.neubiorev.2013.12.002

Cai, H., Cong, W-N., Daimon, C. M., Wang, R., Tschop, M. H., Sevigny, J., Marin, B. & Maudsley, S. (2013). Altered lipid and salt taste responsivity in ghrelin and GOAT null mice. *Plos One, 8*(10), e76553. doi:10.1371/journal.pone.0076553

Calderoni, S., Fantozzi, P., Balboni, G., Pagni, V., Franzoni, E., Apicella, F., Narzisi, A., Maestro, S., & Muratori, F. (2015). The impact of internalizing symptoms on autistic traits in adolescents with restrictive anorexia nervosa. *Neuropsychiatric Disease and Treatment*, 11, 75–85. doi:10.2147/NDT.S73235

Call, N.A., Simmons, C.A>, Mevers, J.E.L. & Alvarez, J.P. (2015). Clinical Outcomes of Behavioral Treatments for Pica in Children with Developmental Disabilities. *Journal of Autism and Developmental Disorders, 45*(7), 2105-2114. doi:10.1007/s10803-015-2375-z

Cameron, E.L. (2018). Olfactory perception in children. *World Journal of Otorhinolaryngology, 4*(1), 57-66. doi:10.1016/j.wjorl.2018.02.002

Caria, A. & de Falco, S. (2015). Anterior insular cortex regulation in autism spectrum disorders. *Frontiers in Behavioral Neuroscience*. doi:10.3389/fnbeh.2015.00038

Carlat, D.J., Camargo, C.A. & Herzog, D.B. (1997). Eating Disorders in Males: A Report on 135 Patients. *American Journal of Psychiatry, 154*(8)*,* 1127-1132*.* doi:10.1176/ajp.154.8.1127

Carrard, I., Crepin, C., Rouget, P., Lam, T., Golay, A. & Van der Linden, M. (2011). Randomised controlled trial of a guided self-help treatment on the Internet for binge eating disorder. *Behaviour Research and Therapy, 49*(8), 482-491. doi: 10.1016/j.brat.2011.05.004

Carter, J.C. & Fairburn, C.G. (1998). Cognitive-behavioral self-help for binge eating disorder: a controlled effectiveness study. *Journal of Consulting and Clinical Psychology, 66*(4), 616-623. doi:10.1037//0022-006x.66.4.616

Carter, J. C., Olmsted, M. P., Kaplan, A. S., McCabe, R.E., Mills, J. S. & Aime, A. (2003). Self-help for bulimia nervosa: a randomized controlled trial. *The American Journal of Psychiatry, 160*(5), 973-978. doi: 10.1176/appi.ajp.160.5.973

Casper, R. C., Kirschner, B., & Jacob, R. A. (1978). Zinc and copper status in anorexia nervosa. *Psychopharmacology Bulletin, 14*(3), 53–55.

Casper, R. C., Kirschner, B., Sandstead, H. H., Jacob, R. A., & Davis, J. M. (1980). An evaluation of trace-metals, vitamins, and taste function in anorexia-nervosa. *American Journal of Clinical Nutrition, 33*(8), 1801– 1808.

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M. & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry, 1*(2), 142-147. doi:10.1016/S2215-0366(14)70248-2

Cassin, S.E., von Ranson, K.M., Heng, K., Brar, J. & Wojtowicz, A.E. (2008). Adapted motivational interviewing for women with binge eating disorder: a randomized controlled trial. *Psychology of Addictive Behaviours, 22*(3), 417-25. doi:10.1037/0893-164X.22.3.417

Castelnuovo, G., Manzoni, G. M., Villa, V., Cesa, G. L., & Molinari, E. (2011). Brief Strategic Therapy vs Cognitive Behavioral Therapy for the Inpatient and Telephone-Based Outpatient Treatment of Binge Eating Disorder: The STRATOB Randomized Controlled Clinical Trial. *Clinical Practice and Epidemiology in Mental Health, 7*, 29–37. doi:10.2174/1745017901107010029

Centers for Disease Control and Prevention (2008). *Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008*. Retrieved from https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm.

Cermak, S. A., Curtin, C. & Bandini, L. G. (2010). Food selectivity and sensory sensitivity in children with autism spectrum disorders. *Journal of the American Dietic Association, 110*(2), 238-246. doi:10.1016/j.jada.2009.10.032.

Chen, E., Touyz, S. W., Beaumont, P. J., Fairburn, C. J., Griffiths, R., Butow, P., Russell, J., Schotte, D.E., Gertler, R. & Basten, C. (2003). Comparison of group and individual cognitive-behavioral

therapy for patients with bulimia nervosa. *International Journal of Eating Disorders, 33*(3), 241-256. doi:10.1002/eat.10137

Cheruel, F., Jarlier, M., & Sancho-Garnier, H. (2017). Effect of cigarette smoke on gustatory sensitivity, evaluation of the deficit and of the recovery time-course after smoking cessation. *Tobacco Induced Diseases, 15*(1), 15. doi:10.1186/s12971-017-0120-4

Cochran, S. V., & Rabinowitz, F. E. (2003). Gender-sensitive recommendations for assessment and treatment of depression in men. *Professional Psychology: Research and Practice, 34*(2), 132–140. doi:10.1037/0735-7028.34.2.132

Cochrane, T. C. (2014). Review Manager 5.3: The Nordic Cochrane Centre.

Cohane, G.H. & Pope, H.G. (2001). Body image in boys: a review of the literature. *International Journal of Eating Disorders, 29*(4), 373-379. doi:10.1002/eat.1033

Collignon, O., Girard, S., Gosselin, F., Saint-Amour, D., Lepore, F. & Lassonde, M. (2010). Women process multisensory emotion expressions more efficiently than men. *Neuropsychologia, 48*(1), 220-225. doi:10.1016/j.neuropsychologia.2009.09.007

Connell, R.W. (1995). *Masculinities*. Berkely, California: University of California Press.

Conner, C.M., Cramer, R.D. & McGonigle, J.J. (2019). Examining the Diagnostic Validity of Autism Measures Among Adults in an Outpatient Clinic Sample. *Autism in Adulthood, 1*(1). doi:10.1089/aut.2018.0023

Cook, R., Brewer, R., Shah, P. & Bird, G. (2013). Alexithymia, Not Autism, Predicts Poor Recognition of Emotional Facial Expressions. *Psychological Science, 24*(5). doi: 10.1177/0956797612463582

Cooney, M., Lieberman, M., Guimond, T., & Katzman, D.K. (2018). Clinical and psychological features of children and adolescents diagnosed with avoidant/restrictive food intake disorder in a pediatric tertiary care eating disorder program: a descriptive study. *Journal of Eating Disorders*, *6*(7). doi:10.1186/s40337-018-0193-3

Cooper, P.J. & Steere, J. (1995). A comparison of two psychological treatments for bulimia nervosa: implications for models of maintenance. *Behaviour Research and Therapy, 33*(8), 875-85. doi:10.1016/0005-7967(95)00033-t

Cooper, K., Loades, M. E., & Russell, A. J. (2018). Adapting Psychological Therapies for Autism - Therapist Experience, Skills and Confidence. *Research in Autism Spectrum Disorders*, *45*, 43–50. doi:10.1016/j.rasd.2017.11.002

Craig, A.D. (2002). How do you feel? Interoception: the sense of the physiological condition of the body. *Nature Reviews Neuroscience, 3*, 655-666. doi:10.1038/nrn894

Craig, A.D. (2009). How Do You Feel- Now? The Anterior Insula and Human Awareness. *Nature Reviews Neuroscience, 10*(1), 59-70. doi:10.1038/nrn2555

Crane, L., Goddard, L. & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. *Autism, 13*(3), 215-28. doi:10.1177/1362361309103794

Critchley, H.D. & Garfinkel, S.N. (2017). Interoception and emotion. *Current Opinion in Psychiatry, 17*, 7-14. doi:10.1016/j.copsyc.2017.04.020

Croen, L.A., Zerbo, O., Qian, Y., Massolo, M.L., Rich, S., Sidne, S. & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism, 19*(7), 814-823. doi:10.1177/1362361315577517

Crucianelli, L., Cardi, V., Treasure, J., Jenkinson, P.M. & Fotopoulou, A. (2016). The Perception of Affective Touch in Anorexia Nervosa. *Psychiatry Research, 239*, 72-78. doi:10.1016/j.psychres.2016.01.078

Cuntz, U., Enck, P., Fruhauf, E., Lehnert, P., Riepl, R. L., Fichter, M. M., & Otto, B. (2013). Cholecystokinin revisited: CCK and the hunger trap in anorexia nervosa. *Plos One, 8*(1), e54457. doi:10.1371/ journal.pone.0054457

Curtin, C., Anderson, S.E., Must, A. & Bandini, L. (2010). The prevalence of obesity in children with autism: a secondary data analysis using nationally representative data from the National Survey of Children's Health. *BMC Pediatrics, 10*. doi:10.1186/1471-2431-10-11

Dahlgren, C.L., Stedal, K. & Ro, O. (2017). Eating Disorder Examination Questionnaire (EDE-Q) and Clinical Impairment Assessment (CIA): clinical norms and functional impairment in male and female adults with eating disorders. *Nordic Journal of Psychiatry, 71*(4), 256-261. doi:1080/08039488.2016.1271452

Dakanalis, A., Timko, A., Clerici, M., Assunta Zanetti, M. & Riva, G. (2014). Comprehensive examination of the trans-diagnostic cognitive behavioural model of eating disorders in males. *Eating Behaviours, 15,* 63-67. doi:10.1016/j.eatbeh.2013.10.003

Damiano, C.R., Aloi, J., Burrus, C., Garbutt, J.C., Kampov-Polevoy, A.B., & Dichter, G.S. (2014). Intact Hedonic Responses to Sweet Tastes in Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, *8*(3), 230–236. doi:10.1016/j.rasd.2013.12.003

Dandil, Y., Baillie, C., & Tchanturia, K. (2019). Cognitive Remediation Therapy as a Feasible Treatment for a Young Person With Anorexia Nervosa and Autism Spectrum Disorder Comorbidity: A Case Study. *Clinical Case Studies*. doi:10.1177/1534650119890425

Dandil, Y. & Smith, K., Adamson, J. & Tchanturia, K. (2020). Individual cognitive remediation therapy benefits for patients with anorexia nervosa and high autistic features. *European Eating Disorders Review, 28*(1), 87-91. doi:10.1002/erv.2707

Dapelo, M.M., Bodas, S., Morris, R. & Tchanturia, K. (2016). Deliberately generated and imitated facial expressions of emotions in people with eating disorders. *Journal of Affective Disorders, 191*, 1-7. doi:10.1016/j.jad.2015.10.044.

Dapelo, M.M., Hart, S., Hale, C., Morris, R. & Tchanturia, K. (2016). Expression of positive emotions differs in illness and recovery in anorexia nervosa. *Psychiatry Research, 246*, 48-51. doi:10.1016/j.psychres.2016.09.014

Darcy, A.M., Doyle, A.C., Lock, J., Peebles, R., Doyle, P., & Le Grange, D. (2012). The Eating Disorders Examination in adolescent males with anorexia nervosa: how does it compare to adolescent females? *The International Journal of Eating Disorders, 45*(1), 110–114. doi:10.1002/eat.20896

David, M. & Hutchinson, C. (2017, July 24). *Panorama: Men, Boys and Eating Disorders*. [Television broadcast]. London: BBC Television.

Davies, H., Wolz, I., Leppanen, J., Fernandez-Aranda, F., Schmidt, U. & Tchanturia, K. (2016). Facial expression to emotional stimuli in non-psychotic disorders: a systematic review and meta-analysis. *Neuroscience and Biobehavioural Reviews, 64*, 252-271. doi:10.1016/j.neubiorev.2016.02.015

Dazzi, F., De Nitto., S., Zambetti, G., Loriedo, C. & Ciofalo, A. (2013). Alterations of the Olfactory–Gustatory Functions in Patients with Eating Disorders. *European Eating Disorders Review, 21*(5), 382-385. doi:10.1002/erv.2238

Dearden, A. & Mulgrew, K. E. (2013). Service Provision for Men with Eating Issues in Australia: An Analysis of Organisations', Practitioners', and Men's Experiences. *Australian Social Work, 66*, 590-606. doi:10.1080/0312407X.2013.778306

DeBar, L. L., Striegel-Moore, R. H., Wilson, G. T., Perrin, N., Yarborough, B. J., Dickerson, J., Lynch, F., Rosselli, F. & Kraemer, H. C. (2011). Guided self-help treatment for recurrent binge eating: replication and extension. *Psychiatric Services, 62*(4), 367–373. doi:10.1176/ps.62.4.pss6204_0367

DeBar, L. L., Wilson, G. T., Yarborough, B. J., Burns, B., Oyler, B., Hildebrandt, T., Clarke, G.N., Dickerson, J. & Striegel, R. H. (2013). Cognitive Behavioral Treatment for Recurrent Binge Eating in

Adolescent Girls: A Pilot Trial. *Cognitive and Behavioral Practice, 20*(2), 147–161. doi:10.1016/j.cbpra.2012.04.001

De Beer, Z. & Wren, B. (2012). Eating Disorders in Males. In Fox J.R. & Goss K.P. (Eds). *Eating and its disorders*. New Jersey: Wiley Online Library.

De Berardis, D., Campanella, D., Nicola, S., Gianna, S., Alessandro, C., Chiara, C., Valchera, A., Marilde, C., Salerno, R.M. & Ferro, F.M. (2008). The Impact of Alexithymia on Anxiety Disorders: a Review of the Literature. *Current Psychiatry Reviews, 4*(2). doi:10.2174/157340008784529287

Den Houting (2018). Neurodiversity: an insider's perspective. *Autism, 23*(2), 271-273. doi:10.1177/1362361318820762

Department of Health (2010). Eliminating Mixed Sex Accomodation. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215932/dh_121860.pdf

Department of Health (2015a). Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

Department of Health (2015b). Mental Health Act 1983: Code of Practice. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF

Desmedt, O., Luminet, O. & Corneille, O. (2018). The heartbeat counting task largely involves non-interoceptive processes: Evidence from both the original and an adapted counting task. *Biological Psychology, 138*, 185-188. doi:10.1016/j.biopsycho.2018.09.004

De Zwaan. (2001). Binge eating disorder and obesity. *International Journal of Obesity, 25*, S51-S55. doi:10.1038/sj.ijo.0801699

Dias, E.C., Rocha, J.S., Ferreira, G.B. & Pena, G.D. (2018). Gluten-free and casein-free diet in autism spectrum disorder: a systematic review. *Revista Cuidarte, 9*(1), 2059-2073. doi:10.15649/cuidarie.v9i1.485

Downs, A. & Smith, T. (2004). Emotional Understanding, Cooperation, and Social Behavior in High-Functioning Children with Autism. *Journal of Autism and Developmental Disorders, 34*, 625-635. doi:10.1007/s10803-004-5284-0

Drewnowski, A., Halmi, K. A., Pierce, B., Gibbs, J., & Smith, G. P. (1987). Taste and eating disorders. *American Journal of Clinical Nutrition, 46*(3), 442–450.

Drewnowski, A., Pierce, B., & Halmi, K. A. (1988). Fat aversion in eating disorders. *Appetite, 10*(2), 119–131.

Dudova, I., & Hrdlicka, M. (2013). Olfactory functions are not associated with autism severity in autism spectrum disorders. *Neuropsychiatric Disease and Treatment*, *9*, 1847–1851. doi:10.2147/NDT.S54893

Dudova, I., Kocourkova, J. & Koutek, J. (2015). Early-onset anorexia nervosa in girls with Asperger syndrome. *Neuropsychiatric Disease and Treatment, 11*, 1639-1643. doi:10.2147/NDT.S83831

Duffy, M.E., Henkel, K.E. & Earnshaw, V.A. (2016) Transgender Clients' Experiences of Eating Disorder Treatment. *Journal of LGBT Issues in Counseling, 10*(3), 136-149. doi:10.1080/15538605.2016.1177806

Dunn, E.C., Neighbors, C. & Larimer, M.E. (2006). Motivational enhancement therapy and self-help treatment for binge eaters. *Psychology of Addictive Behaviours, 20*(1), 44-52. doi:10.1037/0893-164X.20.1.44

Dunn, B.D., Dalgleish, T., Ogilvie, A.D. & Lawrence, A.D. (2007). Heartbeat perception in depression. *Behaviour Research and Therapy, 45*(8), 1921-1930. doi:10.1016/j.brat.2006.09.008

Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist, 70*(3), 255–264. doi:10.1037/a0038636

Durand, M. A., & King, M. (2003). Specialist treatment versus self-help for bulimia nervosa: a randomised controlled trial in general practice. *The British Journal of General Practice: the journal of the Royal College of General Practitioners, 53*(490), 371–377.

Easter, A., & Tchanturia, K. (2011). Therapists' experiences of Cognitive Remediation Therapy for anorexia nervosa: Implications for working with adolescents. *Clinical Child Psychology and Psychiatry, 16*(2), 233–246. doi:10.1177/ 1359104511401185

Eddy, K.T., Thomas, J.J., Hastings, E., Edkins, K., Lamont, E., Nevins, C.M., Patterson, R.M., Murray, H.B., Bryant-Waugh, R. & Becker, A.E. (2015). Prevalence of DSM-5 avoidant/restrictive food intake disorder in a pediatric gastroenterology healthcare network. *International Journal of Eating Disorders, 48*(5), 464-70. doi:10.1002/eat.22350

Edey, R., Cook., J., Brewer, R., Johnson, M.H., Bird, G. & Press, C. (2016). Interaction takes two: Typical adults exhibit mind-blindness towards those with autism spectrum disorder. *Journal of Abnormal Psychology, 125*(7), 879-885. doi:10.1037/abn0000199

Eiber, R., Berlin, I., de Brettes, B., Foulon, C., & Guelfi, J. D. (2002). Hedonic response to sucrose solutions and the fear of weight gain in patients with eating disorders. *Psychiatry Research, 113*(1–2), 173– 180. doi:10.1016/s0165-1781(02)00232-9

Eisler, I., Dare, C., Hodes, M., Russell, G., Dodge, E. & Le Grange, D. (2000). Family therapy for adolescent anorexia nervosa: the results of a controlled comparison of two family interventions. *Journal of Child Psychology and Psychiatry, 41*(6), 727-736. doi:10.1111/1469-7610.00660

Eisler, I., Simic, M., Hodsoll, J., Asen, E., Berelowitz, M., Connan, F., Ellis, G., Hugo, P., Schmidt, U., Treasure, J., Yi, I. & Landau, S. (2016). A pragmatic randomised multi-centre trial of multifamily and single family therapy for adolescent anorexia nervosa. *BMC Psychiatry, 16*(1), 422. doi:10.1186/s12888-016-1129-6

Eizaguirre, A.E., de Cabezon A.O.S., de Alda, I.O., Olariaga, L.J. & Juaniz, M. (2004). Alexithymia and its relationships with anxiety and depression in eating disorders. *Personality and Individual Differences, 1*, 321-331. doi:10.1016/S0191-8869(03)00099-0

Eley, T.C., Stirling, L., Ehlers, A., Gregory, A.M. & Clark, D.M. (2004). Heart-beat perception, panic/somatic symptoms and anxiety sensitivity in children. *Behaviour Research and Therapy, 42*(4), 439-448. doi:10.1016/S0005-7967(03)00152-9

Emerson, E. & Baines, S. (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Stockton-on-Tees: Improving Health and Lives. Retrieved from http://www.improvinghealthandlives.org.uk/projects/autism

Emslie, C., Ridge, D., Ziebland, S., & Hunt, K. (2007). Exploring men's and women's experiences of depression and engagement with health professionals: more similarities than differences? A qualitative interview study. *BMC Family Practice, 8*(43). doi:10.1186/1471-2296-8-43

Equality Act (2010). Retrieved from http://www.legislation.gov.uk/ukpga/2010/15/contents

Eshkevari, E., Rieger, E., Longo, M.R., Haggard, P. & Treasure, J. (2012). Increased plasticity of the bodily self in eating disorders. *Psychological Medicine, 42*(4), 819-828. doi:10.1017/S0033291711002091

Eshkevari, E., Rieger, E., Musiat, P. & Treasure, J. (2014). An investigation of interoceptive sensitivity in eating disorders using a heartbeat detection task and a self-report measure. *European Eating Disorders Review, 22*(5), 383-388. doi:10.1002/erv.2305

Fairburn, C.G. (1986). Cognitive behaviour therapy for bulimia nervosa. *British Review of Bulimia and Anorexia Nervosa*. Available: http://onlinelibrary.wiley.com/o/cochrane/clcentral/articles/507/CN3800709507/frame.html.

Fairburn, C.G., Jones, R., Peveler, R.C., Carr, S.J., Solomon, R.A., O'Connor, M. E., Burton, J. & Hope, R. A. (1992). Three Psychological Treatments for Bulimia Nervosa: A Comparative Trial. *Archives of General Psychiatry, 48*(5):463–469. doi:10.1001/archpsyc.1991.01810290075014

Fairburn, C.G., Cooper, Z., Doll, H., Norman, P. & O'Connor, M. (2000). The Natural Course of Bulimia Nervosa and Binge Eating Disorder in Young Women. *Archives of General Psychiatry, 57*(7), 659-665. doi:10-1001/pubs.Arch Gen Psychiatry-ISSN-0003-990x-57-7-yoa9404

Fairburn, C.G., Cooper, Z., & Shafran, R. (2003). Cognitive behaviour therapy for eating disorders: A "transdiagnostic" theory and treatment. *Behaviour Research and Therapy, 41*(5), 509-28. doi:10.1016/S0005-7967(02)00088-8

Fairburn, C.G. *Cognitive Behavior Therapy and Eating Disorders*. New York: Guilford Press, 2008.

Fairburn, C.G. & Beglin, S. J. Eating Disorder Examination Questionnaire (EDE-Q 6.0). In Fairburn C. G. (Ed.). *Cognitive Behavior Therapy and Eating Disorders.* New York: Guilford Press, 2008.

Fairburn, C.G., Cooper, Z., Doll, H.A., O'Connor, M.E., Bohn, K., Hawker, D.M., Wales, J.A. & Palmer, R.L. (2009). Transdiagnostic cognitive-behavioral therapy for patients with eating disorders: a two-site trial with 60-week follow-up. *The American Journal of Psychiatry, 166*(3), 311–319. doi:10.1176/appi.ajp.2008.08040608

Fairburn, C.G., Bailey-Straebler, S., Basden, S., Doll, H.A., Jones, R., Murphy, R., O'Connor, M.E. & Cooper, Z. (2015). A transdiagnostic comparison of enhanced cognitive behaviour therapy (CBT-E) and interpersonal psychotherapy in the treatment of eating disorders. *Behaviour Research and Therapy, 70*, 64–71. doi:10.1016/j.brat.2015.04.010

Favaro, A., Caregaro, L., Tenconi, E., Bosello, R. & Santonastaso, P. (2009). Time trends in age at onset of anorexia nervosa and bulimia nervosa. *Journal of Clinical Psychiatry, 70*(12), 1715-21. doi:10.4088/JCP.09m05176blu

Ferguson, E. (2013). Personality is of central concern to understand health: towards a theoretical model for health psychology. *Health Psychology Review, 7*(sup1), S32-S70. doi:10.1080/17437199.2010.547985

Fernandez-Aranda, F., Aguera, Z., Fernandez-Garcia, J.C., Garrido-Sanchez, L., Alcaide-Torres, J., Tinahones, F.J., Giner-Bartolome, C., Banos, R. M., Botella, C., Cebolla, A., de la Torre, R., Fernandez-Real, J.M., Orgeta, F.J., Fruhbeck, G., Gomez-Ambrosi, J., Granero, R., Islam, M.A., Jimenez-Murcia, S., Tarrega, S., Menchon, J.M., Fagundo, A.B., Sancho, C., Estivill, X., Treasure, J. & Casanueva, F.F. (2016). Smell-taste dysfunctions in extreme weight/eating conditions: analysis of hormonal and psychological interactions. *Endocrine, 51*(2), 256-67. doi: 10.1007/s12020-015-0684-9.

Fichter, M.M., Quadflieg, N. & Hedlund, S. (2006). Twelve-year Course and Outcome Predictors of Anorexia Nervosa. *International Journal of Eating Disorders, 39*(2), 87-100. doi:10.1002/eat.20215

Fichter, M. M., Quadflieg, N., Nisslmuller, K., Lindner, S., Osen, B., Huber, T. & Wunsch-Leiteritz, W. (2012). Does internet-based prevention reduce the risk of relapse for anorexia nervosa? *Behaviour Research and Therapy, 50*(3), 180-190. doi: 10.1016/j.brat.2011

First, M., Williams, J., Karg., R. & Spitzer, R. (2015). *Structured Clinical Interview for DSM-5, Research Version*. American Psychiatric Association.

Fischer, S., Meyer, A. H., Dremmel, D., Schlup, B. & Munsch, S. (2014). Short-term cognitive-behavioral therapy for binge eating disorder: long-term efficacy and predictors of long-term treatment success. *Behaviour Research and Therapy, 58*, 36-42. doi:10.1016/j.brat.2014.04.007

Fitzgerald, M. & Bellgrove, M.A. (2006). The overlap between alexithymia and asperger's syndrome. *Journal of Autism and Developmental Disorders, 36*, 573. doi:10.1007/s10803-006-0096-z

Fletcher-Watson, S. & Happe, F. (2019). *Autism: A New Introduction to Psychological Theory and Current Debate*. Routledge.

Fodstad, J.C. & Matson, J.L. (2008). A Comparison of Feeding and Mealtime Problems in Adults with Intellectual Disabilities with and Without Autism. *Journal of Developmental and Physical Disabilities, 20*(6), 541-550. doi:10.1007/s10882-008-9116-6

Frank, G. K., Shott, M. E., Hagman, J. O., & Mittal, V. A. (2013). Alterations in brain structures related to taste reward circuitry in ill and recovered anorexia nervosa and in bulimia nervosa. *The American Journal of Psychiatry*, *170*(10), 1152–1160. doi:10.1176/appi.ajp.2013.12101294

Frank, G. K., Shott, M. E., Keffler, C., & Cornier, M. A. (2016). Extremes of eating are associated with reduced neural taste discrimination. *The International Journal of Eating Disorders*, *49*(6), 603–612. doi:10.1002/eat.22538

Freeman, C. P., Barry, F., Dunkeld-Turnbull, J., & Henderson, A. (1988). Controlled trial of psychotherapy for bulimia nervosa. *British Medical Journal, 296*(6621), 521–525. doi:10.1136/bmj.296.6621.521

Freeman, R., Touyz, S., Sara, G., Rennie, C., Gordon, E., & Beumont, P. (1991). In the eye of the beholder: Processing body shape information in anorexic and bulimic patients. *International Journal of Eating Disorders, 10*(6), 709–714. doi:10.1002/1098-108X(199111)10:6<709::AID-EAT2260100609>3.0.CO;2-N

Fukutomi, A., Connan, F., Winston, A. P. & Ghosh, P. (2018). Men in eating disorder units: a service evaluation survey regarding mixed gender accommodation rules in an eating disorder setting. *British Journal of Psychiatry Bulletin, 42,* 258-263. doi:10.1192/bjb.2018.51

Gaigg, S.B. & Bowler, D.M. (2009). Illusory Memories of Emotionally Charged Words in Autism Spectrum Disorder: Further Evidence for Atypical Emotion Processing Outside the Social Domain. *Journal of Autism and Developmental Disorders, 39*, 1031-1038. doi:10.1007/s10803-009-0710-y

Gaigg, S.B. (2012). The interplay between emotion and cognition in autism spectrum disorder: implications for developmental theory. *Frontiers in Integrative Neuroscience*. doi:10.3389/fnint.2012.00113

Gaigg, S.B., Cornell, A.S.F. & Bird, G. (2018). The psychophysiological mechanisms of alexithymia in autism spectrum disorder. *Autism, 22*(2), 227-231. doi:10.1177/1362361316667062

Gale, N.K. Heath, G., Cameron, E., Rashid, S. & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology, 13*. doi:10.1186/1471-2288-13-117

Ganson, K.T., Murray, S.B. & Nagata, J.M. (2019). Last Word: A Call to Develop Specific Medical Treatment Guidelines for Adolescent Males With Eating Disorders. *Eating Disorders, 15*, 1-7. doi:10.1080/10640266.2019.1652474

Garfinkel, S.N., Seth, A., Barret, A.B., Suzuki, K. & Critchley, H.D. (2015). Knowing your own heart: distinguishing interoceptive accuracy from interoceptive awareness. *Biological Psychology, 104*, 65-74. doi:10.1016/j.biopsycho.2014.11.004

Garfinkel, S.N., Tiley, C., O'Keeffe, S., Harrison, N.A., Seth, A.K. & Critchley, H.D. (2016). Discrepancies between dimensions of interoception in autism: Implications for emotion and anxiety. *Biological Psychology, 114*, 117-126. doi:10.1016/j.biopsycho.2015.12.003

Garner, D.M., Olmstead, M.P. & Polivy, J. (1983). Development and validation of a multidimensional eating disorder inventory or anorexia-nervosa and bulimia. *International Journal of Eating Disorders, 2*(2), 15-34. doi:10.1102/1098-108x.(198321)2:2<15::aid-eat2260020203>3.0.co;2-6

Garner, D.M., Rockert, W., Davis, R., Garner, M.V., Olmsted, M. P. & Eagle, M. (1993). Comparison of cognitive-behavioral and supportive-expressive therapy for bulimia nervosa. *American Journal of Psychiatry, 150*(1), 37-46. doi:10.1176/ajp.150.1.37

Gates, S., & Ealing, E. (2019). Reporting and interpretation of results from clinical trials that did not claim a treatment difference: survey of four general medical journals. *BMJ Open*, *9*(9), e024785. doi:10.1136/bmjopen-2018-024785

Geist, R., Heinmaa, M., Stephens, D., Davis, R. & Katzman, D. K. (2000). Comparison of Family Therapy and Family Group Psychoeducation in Adolescents with Anorexia Nervosa. *Canadian Journal of Psychiatry, 45*(2), 173-178. doi:10.1177/070674370004500208

Gibbard, C.R., Ren, J., Skuse, D.H., Clayden, J.D. & Clark, C.A. (2017). Structural connectivity of the amygdala in young adults with autism spectrum disorder. *Human Brain Mapping, 39*(3), 1270-1282. doi:10.1002/hbm.23915

Gillberg, C. (1983). Are autism and anorexia nervosa related? *The British Journal of Psychiatry, 142*, 148.

Godart, N.T., Flament, M.F., Lecrubier, Y. & Jeammet, P. (2000). Anxiety disorders in anorexia nervosa and bulimia nervosa: co-morbidity and chronology of appearance. *European Psychiatry, 15*(1), 38-45. doi:10.1016/s0924-9338(00)00212-1

Godart, N., Berthoz, S., Curt, F., Perdereau, F., Rein, Z., Wallier, J., Horreard, A.S., Kaganski, I., Lucet, R., Atger, F., Corcos, M., Fermanian, J., Falissard, B., Flament, M., Eisler, I. & Jeammet, P. (2012). A randomized controlled trial of adjunctive family therapy and treatment as usual following inpatient treatment for anorexia nervosa adolescents. *PloS One, 7*(1), e28249. doi:10.1371/journal.pone.0028249

Goddard, E., Carral-Fernandez, L., Denneny, E., Campbell, I.C. & Treasure, J. (2014). Cognitive flexibility, central coherence and social emotional processing in males with an eating disorder. *The World Journal of Biological Psychiatry, 15* (4), 317-326. doi:10.3109/15622975.2012.750014

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Prentice Hall.

Goldzak-Kunik, G., Friedman, R., Spitz, M., Sandler, L. & Leshem, M. (2012). Intact sensory function in anorexia nervosa. *The American Journal of Clinical Nutrition, 95*(2), 272- 282. doi:10.3945/ajcn.111.020131

Gordon, K. H., Perez, M. & Joiner, T. E. (2002). The impact of racial stereotypes on eating disorder recognition. *International Journal of Eating Disorders, 32*(2), 219-224. doi:10.1002/eat.10070

Gotestam, K. G., Eriksen, L., Heggestad, T. & Nielsen, S. (1998). Prevalence of eating disorders in Norwegian general hospitals 1990-1994: admissions per year and seasonality. *International Journal of Eating Disorders, 23*(1), 57-64. doi:10.1002/(sici)1098-108x(199801)23:1

Gotham, K., Pickles, A., & Lord, C. (2012). Trajectories of autism severity in children using standardized ADOS scores. *Pediatrics*, *130*(5), e1278–e1284. doi:10.1542/peds.2011-3668

Gould, J. & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice, 12*(1), 34-41.

Gowers, S.G., Clark, A., Roberts, C., Griffiths, A., Edwards, V., Bryan, C., Smethurst, N., Byford, S. & Barrett, B. (2018). Clinical effectiveness of treatments for anorexia nervosa in adolescents: Randomised controlled trial. *British Journal of Psychiatry, 191*, 427-435. doi:10.1192/bjp.bp.107.036764

Graf-Myles, J., Farmer, C., Thurm, A. Royster, C., Kahn, P., Soskey, L., Rothschild, L. & Swedo, S. (2013). Dietary Adequacy of Children with Autism Compared with Controls and the Impact of Restricted Diet. *Journal of Developmental and Behavioral Pediatrics, 34*(7), 449-459. doi:10.1097/DBP.0b013e3182a00d17

Grainger, C., Williams, D.M. & Lind, S.E. (2016). Metacognitive monitoring and control processes in children with autism spectrum disorder: Diminished judgement of confidence accuracy. *Consciousness and Cognition, 42*, 65-74. doi:10.1016/j.concog.2016.03.003

Granich, J., Lin, A., Hunt, A., Wray, J., Dass, A. & Whitehouse, A.J.O. (2016). Obesity and associated factors in youth with an autism spectrum disorder. *Autism, 20*(8), 916-926. doi:10.1177/1362361315616345

Gravestock, S. (2003). Diagnosis and classification of eating disorders in adults with intellectual disability: the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD) approach. *Journal of Intellectual Disability Research, 47*(s1), 72-83. doi:10.1046/j.1365-2788.47.s1.41.x

Green, D., Charman, T., Pickles, A., Chandler, S., Loucas, T., Simonoff, E. & Baird, G. (2009). Impairment in movement skills of children with autistic spectrum disorders. *Developmental Medicine & Child Neurology, 51*(4), 311-316. doi:10.1111/j.1469-8749.2008.03242.x

Griffiths, R. A., Hadzi-Pavlovic, D. & Channon-Little, L. (1994). A controlled evaluation of hypnobehavioural treatment for bulimia nervosa: immediate pre-post treatment effects. *European Eating Disorders Review, 2*(4), 202-220.

Griffiths, S., Murray, S.B. & Touyz, S. (2013). Disordered eating and the muscular ideal. *International Journal of Eating Disorders, 1*(15). doi:10.1186/2050-2974-1-15

Griffiths, S., Murray, S.B., Mond, J. & Touyz, S. (2014). Young People's' Stigmatizing Attitudes and Beliefs about Anorexia Nervosa and Muscle Dysmorphia. *International Journal of Eating Disorders, 47*(2). doi:10.1002/eat.22220

Griffiths, S., Mond, J., Zhicheng, L., Gunatilake, S., Murray, S.B., Sheffield, J. & Touyz, S. (2015). Self-stigma of seeking treatment and being male predict an increased likelihood of having an undiagnosed eating disorder. *International Journal of Eating Disorders, 48*(6), 775-778. doi:10.1002/eat.22413

Griffiths, S., Murray, S.B. & Touyz, S. (2015). Extending the masculinity hypothesis: An investigation of gender role conformity, body dissatisfaction, and disordered eating in young heterosexual men. *Psychology of Men & Masculinity, 16*(1), 108–114. doi:10.1037/a0035958

Grillot, C. L. & Keel, P. K. (2018). Barriers to seeking treatment for eating disorders: The role of self-recognition in understanding gender disparities in who seeks help. *International Journal of Eating Disorders, 51*(11), 1285-1289. doi:10.1002/eat.22965

Grilo, C.M. & Masheb, R.M. (2005). A randomized controlled comparison of guided self-help cognitive behavioral therapy and behavioral weight loss for binge eating disorder. *Behavioural Research and Therapy, 43*(11), 1509-1525. doi:10.1016/j.brat.2004.11.010

Grilo, C.M., Masheb, R.M., Wilson, G.T., Gueorguieva, R., & White, M.A. (2011). Cognitive-behavioral therapy, behavioral weight loss, and sequential treatment for obese patients with binge-eating disorder: a randomized controlled trial. *Journal of Consulting and Clinical Psychology, 79*(5), 675–685. doi:10.1037/a0025049

Grilo, C.M., White, M.A., Gueorguieva, R., Barnes, R.D., & Masheb, R.M. (2013). Self-help for binge eating disorder in primary care: a randomized controlled trial with ethnically and racially diverse obese patients. *Behaviour Research and Therapy*, *51*(12), 855–861. doi:10.1016/j.brat.2013.10.002

Grimm, E.R., & Steinle, N.I. (2011). Genetics of eating behavior: Established and emerging concepts. *Nutrition Reviews, 69*(1), 52–60. doi:10.1111/j.1753-4887.2010.00361.x

Gueguen, J., Godart, N., Chambry, J., Brun-Eberentz, A., Foulon, C., Divac, S.M., Guelfi, J.D., Rouillon, F., Falissard, B. & Huas, C. (2012). Severe anorexia nervosa in men: comparison with severe AN in women and analysis of mortality. *International Journal of Eating Disorders, 45*(4), 537-45. doi:10.1002/eat.20987.

Guestella, A.J., Einfeld, S.L., Gray, K.M., Rinehart, N.J., Tonge, B.J., Lambert, T.J & Hickie, I.B. (2010). Intranasal Oxytocin Improves Emotion Recognition for Youth with Autism Spectrum Disorders. *Biological Psychiatry, 67*(7), 692-694. doi:10.1016/j.biopsych.2009.09.020

Haase, L., Green, E., & Murphy, C. (2011). Males and females show differential brain activation to taste when hungry and sated in gustatory and reward areas. *Appetite*, *57*(2), 421–434. doi:10.1016/j.appet.2011.06.009

Han, P., Keast, R.S.J., & Roura, E. (2017). Salivary leptin and TAS1R2/ TAS1R3 polymorphisms are related to sweet taste sensitivity and carbohydrate intake from a buffet meal in healthy young adults. *British Journal of Nutrition, 118*(10), 763–770. doi:10.1017/ S0007114517002872

Hansen, S. N., Schendel, D. E. & Parner, E. T. (2015). Explaining the increase in the prevalence of autism spectrum disorders: the proportion attributable to changes in reporting practices. *JAMA Pediatrics, 169*(1), 56-62. doi:10.1001/jamapediatrics.2014.1893

Happe, F. & Frith, U. (2006). The Weak Coherence Account: Detail-focused Cognitive Style in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 36*, 5-25. doi:10.1007/s10803-005-0039-0

Harms, M.B., Martin, A. & Wallace, G.L. (2010). Facial Emotion Recognition in Autism Spectrum Disorders: A Review of Behavioral and Neuroimaging Studies. *Neuropsychology Review, 20*, 290-322. doi:10.1007/s11065-010-9138-6

Harrison, A., Sullivan, S., Tchanturia, K. & Treasure, J. (2009). Emotion recognition and regulation in anorexia nervosa. *Clinical Psychology and Psychotherapy, 16*, 348-356. doi:10.1002/cpp.628

Harrison, A., Sullivan, S., Tchanturia, K. & Treasure, J. (2010). Emotional functioning in eating disorder: attentional bias, emotion recognition and emotion regulation. *Psychological Medicine, 40*(11), 1887-1897. doi:10.1017/S0033291710000036

Harrison, A., Tchanturia, K. & Treasure, J. (2010). Attentional bias, emotion recognition, and emotion regulation in anorexia: state or trait? *Biological Psychiatry, 68*(8), 755-61. doi:10.1016/j.biopsych.2010.04.037

Harrison, A., Tchanturia, K. & Treasure, J. (2012). Social emotional functioning and cognitive styles in eating disorders. *British Journal of Clinical Psychology, 51*(3), 261-279. doi:10.1111/j.2044-8260.2011.02026.x

Harrison, A., Mountford, V.A. & Tchanturia, K. (2014). Social anhedonia and work and social functioning in the acute and recovered phases of eating disorders. *Psychiatry Research, 15*, 218. doi:10.1016/j.psychres.2014.04.007

Hartmann, A., Zeek, A. & Barrett, M.S. (2010). Interpersonal Problems in Eating Disorders. *International Journal of Eating Disorders, 43*(7), 619-627. doi: 10.1002/eat.20747

Haviland, M.G., Warren, L. & Riggs, M.L. (2000). An Observer Scale to Measure Alexithymia. *Psychosomatics, 41*(5), 385-392. doi:10.1176/appi.psy.41.5.385

Hay, P.J., Loukas, A., & Philpott, H. (2005). Prevalence and characteristics of men with eating disorders in primary care: How do they compare to women and what features may aid in identification? *Primary Care & Community Psychiatry, 10*(1), 1–6. doi:10.1185/135525705X40346

Hay, P.J., Touyz, S., & Sud, R. (2012). Treatment for severe and enduring anorexia nervosa: A review. *Australian & New Zealand Journal of Psychiatry*, *46*(12), 1136–1144. doi:10.1177/0004867412450469

Health and Social Care Act (2012). Retrieved from http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

Healy, S., Pacanowski, C. & Williams, E. (2019). Weight management interventions for youth with autism spectrum disorder: a systematic review. *International Journal of Obesity, 43*(1), 1-12. doi:10.1038/s41366-018-0233-8

Heaton, P., Riechenbacher, L., Sauter, D., Allen, R., Scott, S. & Hill, E. (2012). Measuring the Effects of Alexithymia on Perception of Emotional Vocalizations in Autistic Spectrum Disorder and Typical Development. *Psychological Medicine, 42*(11), 2453-2459. doi:10.1017/S0033291712000621

Hebebrand, J., Muller, T.D., Holtkamp, K., & Herpertz-Dahlmann, B. (2007). The role of leptin in anorexia nervosa: Clinical implications. *Molecular Psychiatry, 12*(1), 23. doi:10.1038/sj.mp. 4001909

Herbert, B.M., Herbert, C. & Pollatos, O. (2011). On the Relationship Between Interoceptive Awareness and Alexithymia: Is Interoceptive Awareness Related to Emotional Awareness? *Journal of Personality, 79*(5), 1149-1175. doi:10.1111/j.1467-6494.2011.00717.x

Herscovici C.R., Kovalskys, I. & Orellana, L. (2017). An Exploratory Evaluation of the Family Meal Intervention for Adolescent Anorexia Nervosa. *Family Process, 56*(2), 364-375. doi:10.1111/famp.12199

Hibbs, R., Rhind, C., Leppanen, J. & Treasure, J. (2015). Interventions for Caregivers of Someone With an Eating Disorder: A Meta-Analysis. *International Journal of Eating Disorders, 48*(4), 349-361. doi:10.1002/eat.22298

Highet, N., Thompson, M. & King, R.M. (2005). The Experience of Living With a Person With an Eating Disorder: The Impact on the Carers. *Eating Disorders, 13*(4), 327-344. doi:10.1080/10640260591005227

Hilbert, A. & Tuschen-Caffier, B. (2004). Body image interventions in cognitive-behavioural therapy of binge-eating disorder: a component analysis. *Behaviour Research and Therapy, 42*(11), 1325-1339. doi:10.1016/j.brat.2003.09.001

Hill, D.M., Craighead, L.W. & Safer, D.L. (2011). Appetite-focused dialectical behavior therapy for the treatment of binge eating with purging: a preliminary trial. *International Journal of Eating Disorders, 44*(3), 249-261. doi:10.1002/eat.20812

Hill, E. (2004). Evaluating the theory of executive dysfunction in autism. *Developmental Review, 24*(2), 189–233. doi:https://doi.org/10.1016/j.dr.2004.01.001

Hill, E., Berthoz, S. & Frith, U. (2004). Brief Report: Cognitive Processing of Own Emotions in Individuals with Autistic Spectrum Disorder and in Their Relatives. *Journal of Autism and Developmental Disorders, 34*, 229-235. doi:10.1023/B:JADD.0000022613.41399.14

Hiller, R., & Pellicano, L. (2013). Anorexia and autism: A cautionary note. *Psychologist, 26*(11).

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. & Bolte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry, 208*(3), 232-238. doi:10.1192/bjp.bp.114.160192

HM Government. (2014). Think Autism. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

Hobson, H., Westwood, H., Conway, J., McEwen, F.S., Colvert, C., Catmur, C., Bird, G. & Happe, F. (2020). Alexithymia and autism diagnostic assessments: evidence from twins at genetic risk of autism and adults with anorexia nervosa. *Research in Autism Spectrum Disorders, 73*. doi:10.1016/j.rasd.2020.101531

Hoffmann, F., Koehne, S., Steinbeis, N., Dziobek, I., & Singer, T. (2016). Preserved Self-other Distinction During Empathy in Autism is Linked to Network Integrity of Right Supramarginal Gyrus. *Journal of Autism and Developmental Disorders, 46*(2), 637-648. doi:10.1007/s10803-015-2609-0

Holliday, J., Tchantuira, K., Landau, S., Collier, D. & Treasure, J. (2005). Is impaired set-shifting an endophenotype of anorexia nervosa? *The American Journal of Psychiatry, 162*(12), 2269-75. doi:10.1176/appi.ajp.162.12.2269

Hollocks, M.J., Lerh, J.W., Magiati, I., Meiser-Stedman, R. & Brugha, T.S. (2019). Anxiety and Depression in Adults With Autism Spectrum Disorder: A Systematic Review and Meta-Analysis. *Psychological Medicine, 49*(4), 559-572. doi:10.1017/S0033291718002283

Hsu, L. K., Rand, W., Sullivan, S., Liu, D. W., Mulliken, B., McDonagh, B. & Kaye, W. H. (2001). Cognitive therapy, nutritional therapy and their combination in the treatment of bulimia nervosa. *Psychological Medicine, 31*(5), 871-879. doi:10.1017/s003329170100410x

Hudson, J. I., Hiripi, E., Pope, H. G. & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological Psychiatry*, *61*(3), 348–358. doi:10.1016/j.biopsych.2006.03.040

Huke, V., Turk, J., Saeidi, S., Kent, A. & Morgan, J.F. (2013). Autism Spectrum Disorders in Eating Disorder Populations: A Systematic Review. *European Eating Disorder Review, 21*(5), 345-351. doi:10.1002/erv.2244

Huke, V., Turk, J., Saeidi, S., Kent, A. & Morgan, J.F. (2014). The Clinical Implications of High Levels of Autism Spectrum Disorder Features in Anorexia Nervosa: A Pilot Study. *European Eating Disorder Review, 22*(2), 116-121. doi:10.1002/erv.2269

Hull, L. & Mandy, M. (2017). Protective effect or missed diagnosis? Females with autism spectrum disorder. *Future Neurology, 12*(3). doi:10.2217/fnl-2017-0006

Hull, L., Petrides, K.V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C. & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders, 47*(8), 2519-2534. doi:10.1007/s10803-017-3166-5.

Hummel, T., Sekinger, B., Wolf, S.R., Pauli, E. & Kobal, G. (1997). Sniffin' Sticks: Olfactory Performance Assessed by the Combined Testing of Odor Identification, Odor Discrimination and Olfactory Threshold. *Chemical Senses, 22*(1), 39-52. doi:10.1093/chemse/22.1.39

Hummel, T., Kobal, G., Gudziol, H. & Mackay-Sim, A. (2007). Normative data for the "Sniffin' Sticks" including tests of odor identification, odor discrimination, and olfactory thresholds: an upgrade based on a group of more than 3,000 subjects. *European Archives of Oto-Rhino-Laryngology, 264*, 237-243. doi:10.1007/s00405-006-0173-0

Hus, V., & Lord, C. (2014). The Autism Diagnostic Observation Schedule, Module 4: revised algorithm and standardized severity scores. *Journal of Autism and Developmental Disorders*, 44(8), 1996–2012. doi:1007/s10803-014-2080-3

Hyman, S.L., Stewart, P.A., Schmidt, B., Cain, U., Lemcke, N., Foley, J.T., Peck, R., Clemons, T., Reynolds, A., Johnson, C., Handen, B., James, S.J., Manning Courtney, P., Molloy, C. & Ng, P.K. (2012). Nutrient Intake From Food in Children With Autism. *Pediatrics, 130*, S145-S53. doi:10.1542/peds.2012-0900L

Iancu, I, Cohen, E., Ben Yehuda, Y. & Kotler, M. (2006). Treatment of Eating Disorders Improves Eating Symptoms but Not Alexithymia and Dissociation Proneness. *Comprehensive Psychiatry, 47*(3), 189-193. doi: 10.1016/j.comppsych.2006.01.001

Islam, M.A., Fagundo, A.B., Arcelus, J., Aguera, Z., Jimenez-Murcia, S., Fernandez-Real, J.M., Tinahones, F.J., de la Torre, R., Botella, C., Fruhbeck, G., Casanueva, F.F., Menchon, J.M. & Fernandez-Aranda, F. (2015). Olfaction in eating disorders and abnormal eating behaviour: a systematic review. *Frontiers in Psychology, 6*. doi:10.3389/fpsyg.2015.01431

Jacobi, C., Paul, T., de Zwaan, M., Nutzinger, D.O. & Dahme, B. (2004). Specificity of self-concept disturbances in eating disorders. *International Journal of Eating Disorders, 35*(2), 204-210. doi:10.1002/eat.10240

Jaite, C., Hoffmann, F., Glaeske, G. & Bachmann, C.J. (2013). Prevalence, comorbidities and outpatient treatment of anorexia and bulimia nervosa in German children and adolescents. *Eating and Weight Disorders, 18*, 157-165. doi:10.1007/s40519-013-0020-4

Jaworski, M., Panczyk, M., Sliwczynski, A., Brzozowska, M., Janaszek, K., Malkowski., P. & Gotlib, J. (2019). Eating Disorders in Males: An 8-Year Population-Based Observational Study. *American Journal of Men's Health, (13)*4. doi:10.1177/1557988319860970

Jenkinson, P.M., Taylor, L. & Laws, K.R. (2018). Self-reported interoceptive deficits in eating disorders: A meta-analysis of studies using the eating disorder inventory. *Journal of Psychosomatic Research 110*, 38-45. doi:10.1016/j.jpsychores.2018.04.005

Jirik-Babb, P., & Katz, J.L. (1988). Impairment of taste perception in anorexia-nervosa and bulimia. *International Journal of Eating Disorders, 7*(3), 353–360. doi:10.1002/1098-108x(198805) 7:33.0.co;2-y

Joint Commissioning Panel for Mental Health (2013). Guidance for commissioners of eating disorder services. Retrieved from https://www.jcpmh.info/resource/guidance-commissioners-eating-disorder-services/

Jones, M., Luce, K.H., Osborne, M.I., Taylor, K., Cunning, D., Doyle, A.C., Wilfley, D.E. & Taylor, C.B. (2008). Randomized, controlled trial of an internet-facilitated intervention for reducing binge eating and overweight in adolescents. *Pediatrics, 121*(3), 453-62. doi:10.1542/peds.2007-1173.

Kana, R.J., Uddin, L.Q., Kenet, T., Chugani, D. & Muller, R.A. (2014). Brain connectivity in autism. *Frontiers in Human Neuroscience*. doi:10.3389/fnhum.2014.00349

Karjalainen, L., Gillberg, C., Rastam, M. & Wentz, E. (2016). Eating disorders and eating pathology in young adult and adult patietnts with ESSENCE. *Comprehensive Psychiatry, 66*, 79-86. doi:10.1016/j.comppsych.2015.12.009.

Karlsson, K., Rastam, M. & Wentz, E. (2013). The SWedish Eating Assessment for Autism spectrum disorders (SWEAA)-Validation of a self-report questionnaire targeting eating disturbances within the autism spectrum. *Research in Developmental Disabilities 34*(7), 2224-2233. doi:10.1016/j.ridd.2013.03.035

Katsyri, J., Salaasti, S., Tiippana, K., von Wendt, L. & Sams, M. (2008). Impaired recognition of facial emotions from low-spatial frequencies in Asperger syndrome. *Neuropsychologia, 46*(7), 1888-1897. doi:10.1016/j.neuropsychologia.2008.01.005

Kawachi, I., Subramanian, S.V. & Almeida-Filho, N.A. (2002*).* Glossary for Health Inequalities*. Journal of Epidemiology & Community Health, 56*, 647-652. doi:10.1136/jech.56.9.647

Kaye, W.H., Bulik, C.M., Thornton, L., Barbarich, N. & Masters, K. (2004). Comorbidity of anxiety disorders with anorexia and bulimia nervosa. *The American Journal of Psychiatry, 161*(12), 2215-2221. doi:10.1176/appi.ajp.161.12.2215

Kaye, W.H. (2009). Eating Disorders: Hope Despite Mortal Risk. *The American Journal of Psychiatry, 166*(12), 1309-1311. doi:10.1176/appi.ajp.2009.09101424

Kaye, W.H., Fudge, J. L., & Paulus, M. (2009). New insights into symptoms and neurocircuit function of anorexia nervosa. *Nature Reviews Neuroscience, 10*(8), 573. doi:10.1038/nrn2682

Kaye, W.H., Wagner, A., Fudge, J.L., & Paulus, M. (2011). Neurocircuity of eating disorders. *Current Topics in Behavioral Neurosciences, 6*, 37–57. doi:10.1007/7854_2010_85

Kaye, W., Wierenga, C.E., Bailer, F.U., Simmons, A.N. & Bischoff-Grethe, A. (2013). Nothing tastes as good as skinny feels: the neurobiology of anorexia nervosa. *Trends in Neuroscience, 36*(2). doi:10.1016/j.tins.2013.01.003

Kearney-Cooke, A., & Steichen-Asch, P. (1990). Men, Body Image, and Eating Disorders. In Andersen A.E. (Ed.), *Males with Eating Disorders* (pp. 100-115). Brunner/Mazel.

Keating, C., Tilbrook, A.J., Rossell, S.L., Enticott, P.G., & Fitzgerald, P.B. (2012). Reward processing in anorexia nervosa. *Neuropsychologia, 50*(5), 567–575. doi:10.1016/j.neuropsychologia.2012.01.036

Keek, P.K. & Mitchell, J.E. (1997). Outcome in bulimia nervosa. *American Journal of Psychiatry, 154*(3), 131-21. doi:10.1176/ajp.154.3.313

Keller, K.L., Steinmann, L., Nurse, R.J., & Tepper, B.J. (2002). Genetic taste sensitivity to 6-n-propylthiouracil influences food preference and reported intake in preschool children. *Appetite, 38*(1), 3–12. doi:10.1006/appe.2001.0441

Kenny, L., Hattersley, C., Molins, B. Buckley, C., Povey, C. & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442-462. doi:10.1177/1362361315588200

Kerr-Gaffney, J., Harrison, A. & Tchanturia, K. (2020). Autism spectrum disorder traits are associated with empathic abilities in adults with anorexia nervosa. *Journal of Affective Disorders, 266,* 273-281. doi:10.1016/j.jad.2020.01.169

Keshishian, A.C., Tabri, N., Becker, K.R., Franko, D.L., Herzog, D.B., Thomas, J.J. & Eddy, K.T. (2019). Eating disorder recovery is associated with absence of major depressive disorder and substance use disorders at 22-year longitudinal follow-up. *Comprehensive Psychiatry, 90*, 49-51. doi:10.1016/j.comppsych.2019.01.002

Kessler, R.C., Berglund, P.A., Chiu, W.T., Deitz, A.C., Hudson, J.I., Shahly, V., Aguilar-Gaxiola, S., Alonson, J., Angermeyer, M.C., Benjet, C., Bruffaerts, R., de Girolamo, G., de Graaf, R., Haro, J.M., Kovess-Masfety, V., O'Neill, S., Posada-Villa, J., Sasu, C., Scott, K., Viana, M.C. & Xavier, M. (2013). The prevalence and correlates of binge eating disorder in the World Health Organization World Mental Health Surveys. *Biological Psychiatry, 73*(9), 904–914. doi:10.1016/j.biopsych.2012.11.020

Key, A., George, C. L., Beattie, D., Stammers, K., Lacey, H. & Waller, G. (2002). Body image treatment within an inpatient program for anorexia nervosa: The role of mirror exposure in the desensitization process. *International Journal of Eating Disorders, 31*(2), 185-90. doi:10.1002/eat.10027

Khalsa, S.S., Hassanpour, M.S., Strober, M., Craske, M.G., Arevian, A.C. & Feusner, J.D. (2015). Altered interoceptive awareness in anorexia nervosa: Effects of meal anticipation, consumption and bodily arousal. *International Journal of Eating Disorders, 48*(7), 889-897. doi: 10.1002/eat.22387

Khalsa, S.S., & Lapidus, R.C. (2016). Can interoception improve the pragmatic search for biomarkers in psychiatry? *Frontiers in Psychiatry, 7*, 121. doi:10.3389/fpsyt.2016.00121

Khalsa, S.S., Adolphs, R., Cameron, O.G., Critchley, H.D., Davenport, P.W., Feinstein, J.S., Feusner, J.D., Garfinkel, S.N., Lane, R.D., Mehling, W.E., Meuret, A.E., Nemeroff, C.B., Oppenheimer, S., Petzschner, F., Pollatos, O., Rhudy, J.L., Schramm, L.P., Simmons, W.K., Stein, M.B., Stephan, K.E., Van den Bergh, O., Van Deist, I., von Leupoldt, A., Paulus, M.P. & the Interoception Summit 2016 participants. (2018). Interoception and Mental Health: A Roadmap. *Biological Psychiatry, 3*(6), 501-513. doi:10.1016/j.bpsc.2017.12.004

Khalsa, S.S., Hassanpour, M.S., Strober, M., Craske, M.G., Arevian, A.C. & Feusner, J.D. (2018). Interoceptive anxiety and body representation in anorexia nervosa. *Frontiers in Psychiatry, 9*, 444-4. doi:10.3389/fpsyt.2018.00444

Kinnaird, E., Norton, C. & Tchanturia, K. (2017). Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study. *BMC Psychiatry, 17*, 292. doi:10.1007/s40519-019-00770-0

Kinnaird, E. & Norton, C., Tchanturia, K. (2018). Clinicians' views on treatment adaptations for men with eating disorders: a qualitative study. *BMJ Open, 8*. doi:10.1136/bmjopen-2018-021934

Kinnaird, E., Stewart, C. & Tchanturia, K. (2018). Taste sensitivity in anorexia nervosa: A systematic review. *International Journal of Eating Disorders, 51*(8), 771-784. doi:10.1002/eat.22886

Kinnaird, E., Norton, C., Stewart, C. & Tchanturia, K. (2019). Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment? *International Review of Psychiatry, 31*(4), 308-317. doi:10.1080/09540261.2018.1531831

Kinnaird, E., Norton, C., Pimblett, C., Stewart, C. & Tchanturia, K. (2019a). "There's nothing there for guys". Do men with eating disorders want treatment adaptations? A qualitative study. *Eating and Weight Disorders, 24*(5), 845-852. doi:10.1007/s40519-019-00770-0

Kinnaird, E., Norton, C., Pimblett, C., Stewart, C., & Tchanturia, K. (2019b). Eating as an autistic adult: An exploratory qualitative study. *PloS One, 14*(8), e0221937. doi:10.1371/journal.pone.0221937

Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry, (55)*, 80–89 doi:10.1016/j.eurpsy.2018.09.004

Kinnaird, E., Dandil, Y., Li, Z., Smith, K., Pimblett, C., Agbalaya, R., Stewart, C. & Tchanturia, K. (2020). Pragmatic Sensory Screening in Anorexia Nervosa and Associations with Autistic Traits. *Journal of Clinical Medicine, 9*(4). doi:10.3390/jcm9041182.

Kinnaird, E., Stewart, C. & Tchanturia, K. (2020a). The relationship of autistic traits to taste and olfactory processing in anorexia nervosa. *Molecular Autism, 11*(25). doi:10.1186/s13229-020-00331-8

Kinnaird, E., Stewart, C. & Tchanturia, K. (2020b). Interoception in Anorexia Nervosa: Exploring Associations With Alexithymia and Autistic Traits. *Frontiers in Psychiatry*. doi:10.3389/fpsyt.2020.00064

Kjelsas, E., Bjornstrom, C. & Gotestam, K. G. (2004). Prevalence of eating disorders in female and male adolescents (14-15 years). *Eating Behaviours, 5*(1), 13-25. doi:10.1016/S1471-0153(03)00057-6.

Klein, D.A., Schebendach, J.E., Gershkovich, M., Smith, GP., & Walsh, B. T. (2010). Modified sham feeding of sweet solutions in women with anorexia nervosa. *Physiology Behaviour, 101*(1), 132–140. doi:10.1016/j.physbeh.2010.04.030

Klein, U. & Nowak, A.J. (1999). Characteristics of patients with Autistic Disorder (AD) presenting for dental treatment: a survey and chart review. *Special Care in Dentistry, 19*(5), 200-207. doi:10.1111/j.1754-4505.1999.tb01386.x

Knapp-Kline, K. & Kline, J.P. (2005). Heart rate, heart rate variability, and heartbeat detection with the method of constant stimuli: slow and steady wins the race. *Biological Psychology, 69*(3), 387-396. doi:10.1016/j.biopsycho.2004.09.002

Kollndorfer, K., Ohrenberger, I. & Schopf, V. (2016). Contraceptive Use Affects Overall Olfactory Performance: Investigation of Estradiol Dosage and Duration of Intake. *PloS One, 11*(12), e0167520–e. doi:10.1371/journal.pone.0167520

Kooiman, C.G., Spinhoven, P. & Trijsburg, R.W. (2002). The Assessment of Alexithymia: A Critical Review of the Literature and a Psychometric Study of the Toronto Alexithymia Scale-20. *Journal of Psychosomatic Research, 53*(6), 1083-1090. doi:10.1016/s0022-3999(02)00348-3

Kot, E., Kucharska, K., Monteleone, A.M. & Monteleone, P. (2019). Structural and functional brain correlates of altered taste processing in anorexia nervosa: A systematic review. *European Eating Disorders Review, 28*(2), 122-140. doi:10.1002/erv.2713.

Krach, S., Kamp-Becker, I., Einhäuser, W., Sommer, J., Frässle, S., Jansen, A., Rademacher, L., Muller-Pinzler, L., Gazzola, V. & Paulus, F.M. (2015). Evidence from pupillometry and fMRI indicates reduced neural response during vicarious social pain but not physical pain in autism. *Human Brain Mapping, 36*(11), 4730-4744. doi:10.1002/hbm.22949

Kreiser, N.L. & White, S.W. (2014). ASD in Females: Are We Overstating the Gender Difference in Diagnosis? *Clinical Child and Family Psychology Review, 17*(1), 67-84. doi:10.1007/s10567-013-0148-9

Kristeller, J., Wolever, R.Q. & Sheets, V. (2014). Mindfulness-Based Eating Awareness Training (MB-EAT) for Binge Eating: A Randomized Clinical Trial. *Mindfulness, 5*(3), 282-297. doi:10.1007/s12671-012-0179-1

Kuschner, E.S., Eisenberg, I.W., Orionzi, B., Simmons, W.K., Kenworthy, L., Martin, A. & Wallace, G.L. A Preliminary Study of Self-Reported Food Selectivity in Adolescents and Young Adults with Autism Spectrum Disorder. *Research in Autism Spectrum Disorders, 15-16,* 53-59. doi:10.1016/j.rasd.2015.04.005

Kyriacou, O., Easter, A., & Tchanturia, K. (2009). Comparing views of patients, parents and clinicians on emotions in anorexia: A qualitative study. *Journal of Health Psychology, 14*(7), 843–854. doi:10.1177/ 1359105309340977

Lacey, J.H., Stanley, P.A., Crutchfield, M., & Crisp, A.H. (1977). Sucrose sensitivity in anorexia-nervosa. *Journal of Psychosomatic Research, 21*(1), 17–21. doi:10.1016/0022-3999(77)90021-6

Lai, M.C. & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry, 2*(11), 1013-1027. doi:10.1016/S2215-0366(15)00277-1.

Lai, M.C., Lombardo, M.V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: Setting the science for future research. *Journal of the American Academy of Child and Adolescent Psychiatry, 54*(1), 11–24. doi:10.1016/j.jaac.2014.10.003

Lai, M.C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P. & Ameis, S.H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry, 6*(1), 819-829. doi:10.1016/S2215-0366(19)30289-5

Lake, J.K., Perry, A. & Lunsky, Y. (2014). Mental health services for individuals with high functioning autism spectrum disorder. *Autism Research and Treatment*. doi:10.1155/2014/502420

Lan, R., Regester, A., Lauderdale, S., Ashbaugh, K. & Haring, A. (2010). Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: A systematic review. *Developmental Neurorehabilitation, 13*(1), 53-63. doi:10.3109/17518420903236288.

Landis, B.N., Welge-Luessen, A., Bramerson, A., Bende, M., Mueller, C.A., Nordin, S. & Hummel, T. (2009). "Taste Strips"- A rapid, lateralized, gustatory bedside identification test based on impregnated filter papers. *Journal of Neurology, 256*, 242-248. doi:10.1007/s00415-009-0088-y.

Lang, K., Lopez, C., Stahl, D., Tchanturia, K. & Treasure, J. (2014). Central Coherence in Eating Disorders: An Updated Systematic Review and Meta-Analysis. *The World Journal of Biological Psychiatry, 15*(8), 586-589. doi:10.3109/15622975.2014.909606

Lang, K., Stahl, D., Espie, J., Treasure, J., & Tchanturia, K. (2014). Set shifting in children and adolescents with anorexia nervosa: An exploratory systematic review and meta-analysis. *International Journal of Eating Disorders, 47*(4), 394–399. doi:10.1002/eat.22235

Lang, K., Larsson, E.E.C., Mavromara, L., Simic, M., Treasure, J. & Tchanturia, K. (2016). Diminished facial emotion expression and associated clinical characteristics in Anorexia Nervosa. *Psychiatry Research, 236*, 165-172. doi:0.1016/j.psychres.2015.12.004

Lang, K., Roberts, M., Harrison, A., Lopez, C., Goddard, E., Khondoker, M., Treasure, J. & Tchanturia, K. (2016) Central Coherence in Eating Disorders: A Synthesis of Studies Using the Rey Osterrieth Complex Figure Test. *PLoS One, 11*(11): e0165467. doi:10.1371/journal.pone.0165467

Lang, R., Regester, A. Lauderdale, S., Ashbaugh, K. & Haring, A. (2010). Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: A systematic review. *Developmental Neurorehabilitation, 31*(1), 53-63. doi:10.3109/17518420903236288

Larsson, M., Tirado, C., & Wiens, S. (2017). A Meta-Analysis of Odor Thresholds and Odor Identification in Autism Spectrum Disorders. *Frontiers in Psychology, 8*, 679. doi:10.3389/fpsyg.2017.00679

Lartseva, A., Dijkstra, T. & Buitelaar, J.K. (2015). Emotional language processing in autism spectrum disorders: a systematic review. *Frontiers in Human Neuroscience*. doi:10.3389/fnhum.2014.00991

Lavender, A., Startup, H., Naumann, U., Samarawickrema, N., Dejong, H., Kenyon, M., van den Eynde, F. & Schmidt, U. (2012). Emotional and social mind training: a randomised controlled trial of a

new group-based treatment for bulimia nervosa. *PloS One*, *7*(10), e46047. doi:10.1371/journal.pone.0046047

Lavender, J.M., Brown, T.A. & Murray, S.B. (2017). Men, Muscles, and Eating Disorders: an Overview of Traditional and Muscularity-Oriented Disordered Eating. *Current Psychiatry Reports, 19*. doi:10.1007/s11920-017-0787-5

Lee, N.F. & Rush, A.J. (1986). Cognitive-behavioral group therapy for bulimia. *International Journal of Eating Disorders, 5*, 599-615. doi:10.1002/1098-108X(198605)5:4<599::AID-EAT2260050402>3.0.CO;2-W

Le Grange, D., Crosby, R.D., Rathouz, P.J. & Leventhal, B.L. (2007). A Randomized Controlled Comparison of Family-Based Treatment and Supportive Psychotherapy for Adolescent Bulimia Nervosa. *JAMA Psychiatry, 64*(9), 1049-1056. doi:10.1001/archpsyc.64.9.1049

Le Grange, D., Lock, J., Agras, W.S., Bryson, S.W., & Jo, B. (2015). Randomized Clinical Trial of Family-Based Treatment and Cognitive-Behavioral Therapy for Adolescent Bulimia Nervosa. *Journal of the American Academy of Child and Adolescent Psychiatry, 54*(11), 886–94.e2. doi:10.1016/j.jaac.2015.08.008

Leitenberg, H., Rosen, J. C., Gross, J., Nudelman, S. & Vara, L. S. (1988). Exposure plus response-prevention treatment of bulimia nervosa. *Journal of Consulting and Clinical Psychology, 56*(4), 531-41. doi:10.1037//0022-006x.56.4.535

Leppanen, J., Sedgewick, F., Treasure, J. & Tchanturia, K. (2018). Differences in the Theory of Mind profiles of patients with anorexia nervosa and individuals on the autism spectrum: A meta-analytic review. *Neuroscience and Biobehavioural Reviews, 90*, 146-163. doi:10.1016/j.neubiorev.2018.04.009

Levant, R.F. (1995). Toward the reconstruction of masculinity. In Levant, R.F. & W.S. Pollack (Eds.), *A New Psychology of Men* (pp. 229-251). Basic Books.

Levant, R.F., Hall, R.J., Williams, C.M. & Hasan, N.T. (2009). Gender Differences in Alexithymia. *Psychology of Men & Masculinity, 10*(3), 190-203. doi:10.1037/a0015652

Leweke, F., Leichsenring, F., Kruse, J. & Hermes, S. (2012). Is Alexithymia Associated with Specific Mental Disorders. *Psychopathology, 45*, 22-28. doi:10.1159/000325170

Li, S., Zhang, B., Guo, Y. & Zhang, J. (2015). The Association Between Alexithymia as Assessed by the 20-item Toronto Alexithymia Scale and Depression: A Meta-Analysis. *Psychiatry Research, 227*(1), 1-9. doi:10.1016/j.psychres.2015.02.006

Lickel, A., MacLean, W.E., Blakeley-Smith, A. & Hepburn, S. (2012). Assessment of the Prerequisite Skills for Cognitive Behavioral Therapy in Children with and Without Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 42*(6), 992-1000. doi:10.1007/s10803-011-1330-x

Lindner, S.E., Fichter, M.M. & Quadflieg, N. (2014). Set-shifting and Its Relation to Clinical and Personality Variables in Full Recovery of Anorexia Nervosa. *European Eating Disorders Review, 22*(4), 252-259. doi:10.1002/erv.2293

Lindvall Dahlgren, C., Wisting, L. & Ro, O. (2017). Feeding and eating disorders in the DSM-5 era: a systematic review of prevalence rates in non-clinical male and female samples. *Journal of Eating Disorders, 5*(56). doi:10.1186/s40337-017-0186-7

Livingston, L.A. & Livingston, L.M. (2016). Commentary: Alexithymia, not autism, is associated with impaired interoception. *Frontiers in Psychology*. doi:10.3389/fpsyg.2016.01103

Livingston, L.A. & Happe, F. (2017). Conceptualising compensation in neurodevelopmental disorders: Reflections from autism spectrum disorder. *Neuroscience & Biobehavioural Reviews, 80*, 729-742. doi:10.1016/j.neubiorev.2017.06.005.

Livingston, L.A., Shah, P. & Happe, F. (2019). Compensatory strategies below the behavioural surface in autism: a qualitative study. *The Lancet Psychiatry, 6*(9), 766-777. doi:10.1016/S2215-0366(19)30224-X.

Ljotsson, B., Lundin, C., Mitsell, K., Carlbring, P., Ramklint, M. & Ghaderi, A. (2007). Remote treatment of bulimia nervosa and binge eating disorder: a randomized trial of Internet-assisted cognitive behavioural therapy. *Behaviour Research and Therapy, 45*(4), 649-61. doi:10.1016/j.brat.2006.06.010

Lock, J., Agras, W.S., Bryson, S. & Kraemer, H.C. (2005). A Comparison of Short- and Long-Term Family Therapy for Adolescent Anorexia Nervosa. *Journal of the American Academy of Child & Adolescent Psychiatry, 44*(7), 632-639. doi:10.1097/01.chi.0000161647.82775.0a

Lock, J., Le Grange, D., Agras, W.S., Moye, A., Bryson, S.W., & Jo, B. (2010). Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry, 67*(10), 1025–1032. doi:10.1001/archgenpsychiatry.2010.128

Loeb, K.L., Wilson, G.T., Gilbert, J.S. & Labouvie, E. (2000). Guided and unguided self-help for binge eating. *Behaviour Research and Therapy, 38*(3), 259-272. doi:10.1016/s0005-7967(99)00041-8

Lombardo, M.V., Barnes, J.L., Wheelwright, S.J., & Baron-Cohen, S. (2007). Self-Referential Cognition and Empathy in Autism. *Plos One, 2*(9), e883. doi:10.1371/journal.pone.0000883

Lombion-Pouthier, S., Vandel, P., Nezelof, S. Haffen, E. & Millot, J.L. (2006). Odor Perception in Patients With Mood Disorders. *Journal of Affective Disorders, 90*(2-3), 187-191. doi:10.1016/j.jad.2005.11.012

Loomes, R., Hull, L. & Mandy, W. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child and Adolescent Psychiatry, 56*(6), 466-474. doi:10.1016/j.jaac.2017.03.013

Lord, C., Rutter, M. & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A Revised version of a Diagnostic Interview for Caregivers of Individuals with Possible Pervasive Developmental Disorders. *Journal of Autism and Developmental Disorders, 24*(5), 659-85. doi:10.1007/BF02172145.

Lord, C., Risi, S., Lambrecht, L., Cook, E.H., Leventhal, B.L., DiLavore, P.C., Pickles, A. & Rutter, M. (2000). The autism diagnostic observation schedule—generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders, 30*(3), 205–223. doi:10.1023/a: 1005592401947

Lord, C., & Jones, R. M. (2012). Annual research review: re-thinking the classification of autism spectrum disorders. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *53*(5), 490–509. doi:10.1111/j.1469-7610.2012.02547.x

Losh, M. & Capps, L. (2006). Understanding of Emotional Experience in Autism: Insights From the Personal Accounts of High-Functioning Children With Autism. *Developmental Psychology, 42*(5), 809-818. doi:10.1037/0012-1649.42.5.809

Lounes, N., Khan, G. & Tchanturia, K. (2011). Assessment of Cognitive Flexibility in Anorexia Nervosa--Self-Report or Experimental Measure? A Brief Report. *Journal of the International Neuropsychological Society, 17*(5), 925-928. doi:10.1017/S1355617711000671

Luborsky, L., McLellan, T., Woody, G.E., O'Brien, C.P. & Auerbach, A. (1985). Therapist Success and Its Determinants. *Archives of General Psychiatry, 42*(6), 602-611. doi:10.1001/archpsyc.1985.01790290084010

Lumley, M.A., Neely, L.C. & Burger, A.J. (2007). The Assessment of Alexithymia in Medical Settings: Implications for Understanding and Treating Health Problems. *Journal of Personality Assessment, 89*(3), 230-246. doi:10.1080/00223890701629698

Lutz, A. P. C., Shulz, A., Voerholzer, U., Kock, S., van Dyck, Z., Vogele, C. (2019). Enhanced cortical processing of cardio-afferent signals in anorexia nervosa. *Clinical Neurophysiology, 130*(9), 1620-27. doi:10.1016/j.clinph.2019.06.009

Lyons, G., McAndrew, S. & Warne, T. (2019). Disappearing in a Female World: Men's Experiences of Having an Eating Disorder (ED) and How It Impacts Their Lives. *Issues in Mental Health Nursing, 40*(7), 557-566. doi:10.1080/01612840.2019.1576815

MacCaughelty, C., Wagner, R. & Rufino, K. (2016). Does being overweight or male increase a patient's risk of not being referred for an eating disorder consult?. *International Journal of Eating Disorders, 49*(10), 963-966. doi:10.1002/eat.22556

Machado, B.C., Vieira, A.I., Brandao, I., Buinhas, I., Granja, N., Cunha, M., Sa, J., Machado, J., Timoteo, S., Nunes, P. & Goncalves, S. (2020). Eating Disorders in Males: A Case Series Study to Evaluate Putative Risk Factors. *The Journal of Men's Studies.* doi:10.1177/1060826520905093

MacNeil, B.A., Hudson, C.C. & Leung, P. (2018). It's raining men: descriptive results for engaging men with eating disorders in a specialized male assessment and treatment track (MATT). *Eating and Weight Disorders, 23*, 817-824. doi:10.1007/s40519-018-0586-y

Madill, A., Jordan, A. & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*, 21-20. doi:10.1348/000712600161646

Madsen, S. K., Bohon, C., & Feusner, J. D. (2013). Visual processing in anorexia nervosa and body dysmorphic disorder: similarities, differences, and future research directions. *Journal of Psychiatric Research*, *47*(10), 1483–1491. doi:10.1016/j.jpsychires.2013.06.003

Magiati, I., Tay, X.W. & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review, 34*(1), 73-86. doi:10.1016/j.cpr.2013.11.002

Mai, Y., Zhang, X., Li, Z., Wu, X., Zeng, B., Fang, Y., Zou, L., Zhao, J. & Hummel, T. (2020). Olfaction is a Marker of Severity but Not Diagnosis in Anorexia Nervosa: a Systematic Review and Meta-Analysis. *Neuropsychology Review*. doi:10.1007/s11065-020-09438-4

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A. & Skuse, D. (2012). Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders, 42*(7), 1304-1313. doi:10.1007/s10803-011-1356-0.

Mandy, W. & Tchanturia, K. (2015). Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. *Molecular Autism, 6*. doi:10.1186/2040-2392-6-6

Mari-Bauset, S., Llopis-Gonzalez, A., Zazpe, I., Mari-Sanchis, A. & Suarez-Varela, M.M. (2017). Comparison of nutritional status between children with autism spectrum disorder and typically developing children in the Mediterranean Region (Valencia, Spain). *Autism, 21*(3), 310-322. doi:10.1177/1362361316636976

Marshall, J., Hill, R.J., Ziviani, J. & Dodrill, P. (2014). Features of feeding difficulty in children with Autism Spectrum Disorder. *International Journal of Speech-Language Pathology, 16*(2), 151-158. doi:10.3109/17549507.2013.808700

Mason, T.B. & Lewis, R.J. (2015). Assessing the roles of impulsivity, food-related cognitions, BMI, and demographics in the dual pathway model of binge eating among men and women. *Eating Behaviours, 18*, 151-155. doi:10.1016/j.eatbeh.2015.05.015

Masson, P.C., von Ranson, K.M., Wallace, L.M. & Safer, D.L. (2013). A randomized wait-list controlled pilot study of dialectical behaviour therapy guided self-help for binge eating disorder. *Behaviour Research and Therapy, 51*(11), 723-728. doi:10.1016/j.brat.2013.08.001

Matheson B.E. & Douglas, J.M. (2017). Overweight and Obesity in Children with Autism Spectrum Disorder (ASD): a Critical Review Investigating the Etiology, Development, and Maintenance of this Relationship. *Review Journal of Autism and Developmental Disorders, 4,* 142-156. doi:10.1007/s40489-017-0103-7

Mattes, R.D. (1985). Gustation as a determinant of ingestion: Methodological issues. *American Journal of Clinical Nutrition, 41*(4), 672–683

Mattes, R.D. (2011). Accumulating evidence supports a taste component for free fatty acids in humans. *Physiology Behaviour, 104*(4), 624–631. doi:10.1016/j.physbeh.2011.05.002

Mattila, A.K., Salminen, J.K., Nummi, T. & Joukamaa, M. (2006). Age is strongly associated with alexithymia in the general population. *Journal of Psychosomatic Research, 61*(5), 629-635. doi:10.1016/j.jpsychores.2006.04.013

McCormack, M. & Anderson, E. (2014). The Influence of Declining Homophobia on Men's Gender in the United States: An Argument for the Study of Homohysteria. *Sex Roles, 71*, 109-120. doi:10.1007/s11199-014-0358-8

McCrickerd, K., & Forde, C. G. (2016). Sensory influences on food intake control: Moving beyond palatability. *Obesity Reviews, 17*(1), 18–29. doi:10.1111/obr.12340

McElhanon, B.O., McCracken, C., Karpen, S. & Sharp, W.G. (2014). Gastrointestinal Symptoms in Autism Spectrum Disorder: A Meta-analysis. *Pediatrics, 133*(5), 872-883. doi:10.1542/peds.2013-3995

McIntosh, V.V., Jordan, J., Luty, S.E., Carter, F.A., McKenzie, J.M. & Bulik, C.M. & Joyce, P.R. (2006). Specialist supportive clinical management for anorexia nervosa. *International Journal Eating Disorders,* 38(8), 625-32. doi:10.1002/eat

McIntosh, V.V., Jordan, J., Carter, J.D., Framptom, C.M., McKenzie, J.M., Latner, J.D & Joyce, P.R. (2016). Psychotherapy for transdiagnostic binge eating: A randomized controlled trial of cognitive-behavioural therapy, appetite-focused cognitive-behavioural therapy, and schema therapy. *Psychiatry Research, 30*(240), 412-420. doi:10.1016/j.psychres.2016.04.080

McManus, S, Bebbington, P, Jenkins, R, Brugha, T. (eds.) (2016). *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014*. Leeds: NHS Digital.

Mechling, L.C., Ayres, K.M., Foster, A.L. & Bryant, K.J. (2013). Comparing the Effects of Commercially Available and Custom-Made Video Prompting for Teaching Cooking Skills to High School Students With Autism. *Remedial and Special Education, 34*(6), 371-383. doi: 10.1177/0741932513494856

Mehler, P.S., Sabel, A.L., Watson, T. & Andersen, A.E. (2008). High risk of osteoporosis in male patients with eating disorders. *International Journal of Eating Disorders, 41*(7), 666-72. doi:10.1102/eat.20554

Merwin, R.M., Moskovich, A.A., Wager, H.R., Ritschel, L.A., Craighead, L.W., Zucker, N.L. (2013). Emotion regulation difficulties in anorexia nervosa: Relationship to self-perceived sensory sensitivity. *Cognition and Emotion, 27*, 441-452. doi:10.1080/02699931.2012.719003

Micali, N., Hagberg, K. W., Petersen, I., & Treasure, J. L. (2013). The incidence of eating disorders in the UK in 2000-2009: findings from the General Practice Research Database. *BMJ Open, 3*(5). doi:10.1136/bmjopen-2013-002646

Mickalide, A.D. (1990). Sociocultural Factors Influencing Weight Among Males. In Andersen A.E. (Ed.), *Males with Eating Disorders* (pp. 100-115). Brunner/Mazel.

Milner, V., McIntosh, H., Colvert, E., & Happé, F. (2019). A Qualitative Exploration of the Female Experience of Autism Spectrum Disorder (ASD). *Journal of Autism and Developmental Disorders*, *49*(6), 2389–2402. doi:10.1007/s10803-019-03906-4

Milosavljevic, B., Carter Leno, V., Simonoff, E., Baird, G., Pickles, A., Jones, C.R.G., Erskine, C., Charman, T. & Happe, F. (2015). Alexithymia in Adolescents with Autism Spectrum Disorder: Its

Relationship to Internalising Difficulties, Sensory Modulation and Social Cognition. *Journal of Autism and Developmental Disorders, 46*, 1354-1367. doi: 10.1007/s10803-015-2670-8

Milton, D. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society, 27*(6), 883-887. doi:10.1080/09687599.2012.710008.

Milton, D. (2014). So what exactly are autism interventions intervening with? *Good Autism Practice, 15*(2), 6-14.

Mitchell, J.E., Pyle, R.L., Pomeroy, C., Zollman, M., Crosby, R., Seim, H., Eckert, E.D. & Zimmerman, R. (1993). Cognitive-behavioral group psychotherapy of bulimia nervosa: importance of logistical variables. *International Journal of Eating Disorders, 14*(3), 277-287. doi:10.1002/1098-108x(199311)14:3<277::aid-eat2260140306>3.0.co;2-8

Mitchell, J E., Crosby, R.D., Wonderlich, S.A., Crow, S., Lancaster, K., Simonich, H., Swan-Kremeier, L., Lysne, C. & Myers, T.C. (2008). A randomized trial comparing the efficacy of cognitive-behavioral therapy for bulimia nervosa delivered via telemedicine versus face-to-face. *Behaviour Research and Therapy, 46*(5), 581–592. doi:10.1016/j.brat.2008.02.004

Mitchison, D., Hay, P., Slewa-Younan, S. & Mond, J. (2014). The changing demographic profile of eating disorder behaviours in the community. *BMC Public Health, 11*. doi:10.1186/1471-2458-14-943.

Mitchison, D. & Mond, J. (2015). Epidemiology of eating disorders, eating disordered behaviour, and body image disturbance in males: a narrative review. *International Journal Eating Disorders, 3*(20). doi:10.1186/s40337-015-0058-y

Moher, D., Liberati, A., Tezlaff, J. & Altman, D.G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ*, 339:b2535. doi:10.1136/bmj.b2535

Mond, J.M., Hay, P.J., Rodgers, B. & Owen, C. (2006). Eating Disorder Examination Questionnaire (EDE-Q): norms for young adult women. *Behaviour Research and Therapy, 44*(1), 53-62. doi:10.1016/j.brat.2004.12.003

Money, C., Genders, R., Treasure, J., Schmidt, U., & Tchanturia, K. (2011). A brief emotion focused intervention for inpatients with anorexia nervosa: A qualitative study. *Journal of Health Psychology*, *16*(6), 947–958. doi:10.1177/1359105310396395

Montebarocci, O., Codispoti, M., Surcinelli, P., Franzoni, E., Baldaro, B. & Rossi, N. (2006). Alexithymia in female patients with eating disorders. *Eating and Weight Disorders, 11*(1), 14-21. doi:10.1007/bf03327739

Monteleone, A.M., Monteleone, P., Esposito, F., Prinster, A., Volpe, U., Cantone, E., Pellegrino, F., Canna, A., Milano, W., Aiello, M., Di Salle, F. & Maj, M. (2017). Altered processing of rewarding and aversive basic taste stimuli in symptomatic women with anorexia nervosa and bulimia nervosa: An fMRI study. *Journal of Psychiatric Research, 90*, 94–101. doi:10.1016/j.jpsychires.2017.02. 013

Moore, B.N. & Davis T. E. (2010). Cognitive-behavioral therapy for anxiety in children diagnosed with autism spectrum disorders: Modification trends. *Research in Autism Spectrum Disorders, 4*(3), 346-354. doi:10.1016/j.rasd.2009.10.015

Morgan, J.F., Key, A., Hubert Lacey, J. (1998). Gender issues in the management of multi-impulsive bulimia: A case-study. *International Journal of Eating Disorders, 24*(1), 107-109. doi:10.1002/(SICI)1098-108X(199807)24:1<107::AID-EAT11>3.0.CO;2-Y

Morgan, J.F. (2008). *The Invisible Man: A self-help guide for men with eating disorders, compulsive exercise and bigorexia.* Routledge.

Morgan, J.F. & Arcelus, J. (2009). Body image in gay and straight men: a qualitative study. *European Eating Disorders Review, 17*(6), 435-43. doi:10.1002/erv.955.

Moriguchi, Y., Ohnishi, T., Lane, R.D., Maeda, M., Mori, T., Nemoto, K., Matsuda, H. & Komaki, G. (2006). Impaired self-awareness and theory of mind: An fMRI study of mentalizing in alexithymia. *NeuroImage, 32*(3), 1472-1482. doi:10.1016/j.neuroimage.2006.04.186

Mueller, C., Kallert, S., Renner, B., Stiassny, K., Temmel, A.F., Hummel, T. & Kobal, G. (2003). Quantitative assessment of gustatory function in a clinical context using impregnated “taste strips”. *Rhinology, 41*(1), 2-6.

Mul, C.L., Stagg, S.D., Herbelin, B. & Aspell, J.E. (2018). The feeling of me feeling for you: interoception, alexithymia and empathy in autism. *Journal of Autism and Developmental Disorders, 48*(9), 2953-2967. doi:10.1007/s10803-018-3564-3

Muller, J., Buhner, M. & Ellgring, H. (2003). Is There a Reliable Factorial Structure in the 20-item Toronto Alexithymia Scale? A Comparison of Factor Models in Clinical and Normal Adult Samples. *Journal of Psychosomatic Research, 55*(6), 561-568. doi:10.1016/s0022-3999(03)00033-3

Muller, J., Buhner, M. & Ellgring, H. (2004). The assessment of alexithymia: psychometric properties and validity of the Bermond–Vorst alexithymia questionnaire. *Personality and Individual Differences, 37*(2), 373-391. doi:10.1016/j.paid.2003.09.010

Mullol, J., Alobid, I., Mariño-Sánchez, F., Quintó, L., de Haro, J., Bernal-Sprekelsen, M., Valero, A., Picado, C., & Marin, C. (2012). Furthering the understanding of olfaction, prevalence of loss of smell

and risk factors: a population-based survey (OLFACAT study). *BMJ Open*, *2*(6), e001256. doi:10.1136/bmjopen-2012-001256

Munsch, S., Biedert, E., Meyer, A., Michael, T., Schlup, B., Tuch, A. & Margraf, J. (2007). A randomized comparison of cognitive behavioral therapy and behavioral weight loss treatment for overweight individuals with binge eating disorder. *International Journal of Eating Disorders, 40*(2), 102-113. doi:10.1002/eat.20350

Muratori, F., Tonacci, A., Billeci, L., Catalucci, T., Igliozzi, R., Calderoni, S. & Narzisi, A. (2017). Olfactory Processing in Male Children With Autism: Atypical Odor Threshold and Identification. *Journal of Autism and Developmental Disorders, 47*(10), 3243-3251. doi:10.1007/s10803-017-3250-x

Murphy, J., Brewer, R., Hobson, H., Catmur, C. & Bird, G. (2018). Is alexithymia characterised by impaired interoception? Further evidence, the importance of control variables, and the problems with the Heartbeat Counting Task. *Biological Psychology, 136*, 189-197. doi:10.1016/j.biopsycho.2018.05.010

Murphy, J., Catmur, C. & Bird, G. (2018). Alexithymia is associated with a multidomain, multidimensional failure of interoception: Evidence from novel tests. *Journal of Experimental Psychology: General, 147*(3), 398-408. doi:10.1037/xge0000366

Murphy, J., Catmur, C. & Bird, G. (2019). Classifying individual differences in interoception: Implications for the measurement of interoceptive awareness. *Psychonomic Bulletin & Review, 26*, 1467-1471. doi:10.3758/s13423-019-01632-7

Murray, K., Johnston, K., Cunnane, H., Kerr, C., Spain, D., Gillan, N., Hammond, N., Murphy, D. & Happé, F. (2017). A new test of advanced theory of mind: The “Strange Stories Film Task” captures social processing differences in adults with autism spectrum disorders. *Autism Research, 10*(6), 1120-1132. doi:10.1002/aur.1744

Murray, S.B., Rieger, E., Touyz, S.W., De la Garza Garcia, Y. L. (2010). Muscle dysmorphia and the DSM-V conundrum: Where does it belong? A review paper. *International Journal of Eating Disorders, 43*(6), 483-491. doi:10.1002/eat.20828

Murray, S.B., Rieger, E., Hildebrandt, T., Karlov, K., Russell, J., Boon, E., Dawson, R.T. & Touyz, S.W. (2012). A comparison of eating, exercise, shape, and weight related symptomatology in males with muscle dysmorphia and anorexia nervosa. *Body Image, 9*(2), 193-200. doi:10.1016/j.bodyim.2012.01.008

Murray, S.B., Rieger, E., Karlov, L. & Touyz, S.W. (2012). An Investigation of the Transdiagnostic Model of Eating Disorders in the Context of Muscle Dysmorphia. *European Eating Disorders Review, 21*(2), 160-164. doi:10.1002/erv.2194

Murray, S.B., Rieger, E., Karlov, L., & Touyz, S.W. (2013) Masculinity and femininity in the divergence of male body image concerns. *International Journal of Eating Disorders, 1*(11). doi:10.1186/2050-2974-1-11

Murray, S.B., Griffiths, S., Rieger., E & Touyz, S. (2014) A comparison of compulsive exercise in male and female presentations of anorexia nervosa: what is the difference? *Advances in Eating Disorders*, *2*(1), 65-70, doi:10.1080/21662630.2013.839189

Murray, S. B, Griffiths, S. & Mond, J.M. (2016). Evolving eating disorder psychopathology: Conceptualizing muscularity-oriented disordered eating. *British Journal of Psychiatry, 208*(5), 414-15. doi:10.1192/bjp.bp.115.168427

Murray, S. B., Nagata, J. M., Griffiths, S., Calzo, J.P., Brown T. A., Mitchison, D., Blashill, A.J. & Mond, J.M. (2017). The enigma of male eating disorders: A critical review and synthesis. *Clinical Psychology Review, 57*, 1-11. doi:10.1016/j.cpr.2017.08.001.

Murray, S.B., Accurso, E.C., Griffiths, S. & Nagata, J.M. (2018). Boys, Biceps, and Bradycardia: The Hidden Dangers of Muscularity-Oriented Disordered Eating. *Journal of Adolescent Health, 62*(3), 352-355. doi:10.1016/j.jadohealth.2017.09.025

Nadon, G., Ehrmann Feldman, D., Dunn, W. & Gisel, E. (2011). Association of sensory processing and eating problems in children with autism spectrum disorders. *Autism Research and Treatment*. doi:10.1155/2011/541926

Nagata, J.M., Park, K.T., Colditz, K. & Golden, N.H. (2015). Associations of elevated liver enzymes among hospitalized adolescents with anorexia nervosa. *The Journal of Pediatrics 166*(2), 439-43. doi:10.1016/j.jpeds.2014.10.048

Najafizade, N., Hemati, S., Gookizade, A., Berjis, N., Hashemi, M., Vejdani, S., Ghannadi, A., Armindokht, S. & Arbab, N. (2013). Preventive effects of zinc sulfate on taste alterations in patients under irradiation for head and neck cancers: A randomized placebo-controlled trial. *Journal of Research in Medical Sciences, 18*(2), 123–126.

Nakai, Y., Kinoshita, F., Koh, T., Tsujii, S., & Tsukada, T. (1987). Taste function in patients with anorexia-nervosa and bulimia-nervosa. *International Journal of Eating Disorders, 6*(2), 257–265. doi:10.1002/1098-108x(198703)6:23.0.co;2-x

Nam, S.K., Chu, H.J., Lee, M.K., Lee, J.H. & Lee, S.M. (2010). A meta-analysis of gender differences in attitudes toward seeking professional psychological help. *Journal of American College Health, 59*(2), 110-116. doi:10.1080/07448481.2010.483714

Narzisi, A., Murtatori, F., Calderoni, S., Fabbro, F. & Urgesi, C. (2013). Neuropsychological Profile in High Functioning Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 43*(8), 1895-1909. doi:10.1007/s10803-012-1736-0

National Institute for Health and Care Excellence. (2016). Autism spectrum disorder in adults: diagnosis and management (NICE guideline No. 142). Retrieved from https://www.nice.org.uk/guidance/cg142

National Institute for Health and Care Excellence. (2017). Eating Disorders: Recognition and Treatment (NICE Guideline No. 69). Retrieved from https://www.nice.org.uk/guidance/ng69

Nauta, H., Hospers, H., Kok, G. & Jansen, A. (2000). A comparison between a cognitive and a behavioral treatment for obese binge eaters and obese non-binge eaters. *Behavior Therapy, 31*(3), 441-461. doi:10.1016/S0005-7894(00)80024-6

Nauta, H., Hospers, H. & Jansen, A. (2001). One-year follow-up effects of two obesity treatments on psychological well-being and weight. *British Journal of Health Psychology, 6*(3), 271-84. doi:10.1348/135910701169205

Nazar, B.P., Peynenburg, V., Rhind, C., Hibbs, R., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Micali, N. & Treasure, J. (2018). An examination of the clinical outcomes of adolescents and young adults with broad autism spectrum traits and autism spectrum disorder and anorexia nervosa: A multi centre study. *International Journal of Eating Disorders, 51*(2), 174-179. doi:10.1002/eat.22823

Neil, L., Olsson, N.C., & Pellicano, E. (2016). The Relationship Between Intolerance of Uncertainty, Sensory Sensitivities, and Anxiety in Autistic and Typically Developing Children. *Journal of Autism and Developmental Disorders*, *46*(6), 1962–1973. doi:10.1007/s10803-016-2721-9

Nevonen, L. & Broberg, A. G. (2006). A comparison of sequenced individual and group psychotherapy for patients with bulimia nervosa. *International Journal of Eating Disorders, 39*(2), 117-127. doi:10.1002/eat.20206

NHS England (2015). Guidance for NHS commissioners on equality and health inequalities legal duties. Retrieved from https://www.england.nhs.uk/wp-content/uploads/2015/12/hlth-inqual-guid-comms-dec15.pdf

NHS England (2019). Adult eating disorders: community, inpatient and intensive day patient care. Guidance for commissioners and providers. Retrieved from https://www.england.nhs.uk/wp-content/uploads/2019/08/aed-guidance.pdf

NHS England & NHS Improvement (2019). Delivering Same-Sex Accomodation. Retrieved from https://improvement.nhs.uk/documents/6005/Delivering_same_sex_accommodation_sep2019.pdf

Nicely, T. A., Lane-Loney, S., Masciulli, E., Hollenbeak, C. S., & Ornstein, R. M. (2014). Prevalence and characteristics of avoidant/restrictive food intake disorder in a cohort of young patients in day treatment for eating disorders. *Journal of Eating Disorders*, *2*(1), 21. doi:10.1186/s40337-014-0021-3

Nicholls, D.E., Lynn, R. & Viner, R.M. (2011). Childhood Eating Disorders: British National Surveillance Study. *The British Journal of Psychiatry, 198*(4), 295-301. doi:10.1192/bjp.bp.110.081356

Nicholson, T. M., Williams, D. M., Grainger, C., Christensen, J. F., Calvo-Merino, B., & Gaigg, S. B. (2018). Interoceptive impairments do not lie at the heart of autism or alexithymia. *Journal of Abnormal Psychology*, *127*(6), 612–622. doi:10.1037/abn0000370

Nicholson, T., Williams, D., Carpenter, K. & Kallitsounaki, A. (2019). Interoception is impaired in children, but not adults, with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49*(9), 3625-3637. doi:10.1007/s10803-019-04079-w

Nickel, K., Maier, S., Endres, D., Joos, A., Maier, V., Tebartz van Elst, L. & Zeeck, A. (2019). Systematic Review: Overlap Between Eating, Autism Spectrum, and Attention-Deficit/Hyperactivity Disorder. *Frontiers in Psychiatry*. doi:10.3389/fpsyt.2019.00708

Nicolaidis, C. (2012). What Can Physicians Learn from the Neurodiversity Movement? *Virtual Mentor, 14*(6), 503-510. doi:10.1001/virtualmentor.2012.14.6.oped1-1206.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*, *28*(6), 761–769. doi:10.1007/s11606-012-2262-7

Nielsen, S., Anckarsater, H., Gillberg, C., Gillberg, C., Rastam, M. & Wentz, E. (2015). Effects of autism spectrum disorders on outcome in teenage-onset anorexia nervosa evaluated by the Morgan-Russell outcome assessment schedule: a controlled community-based study. *Molecular Autism, 6*(14). doi:10.1186/s13229-015-0013-4

Nozoe, S. I., Masuda, A., Naruo, T., Soejima, Y., Nagai, N., & Tanaka, H. (1996). Changes in taste responsiveness in patients with anorexia nervosa during behavior therapy. *Physiology Behavior, 59*(3), 549– 553. doi:10.1016/0031-9384(95)02105-1

Nunez-Navarro, A., Aguera, Z., Krug, I., Jimenez-Murcia, S., Sanchez, I., Araguz, N., Gorwood, P., Granero, R., Penelo., E., Karwautz, A., Moragas, L., Saldana, S., Treasure, J., Menchon, J.M. & Fernandez-Aranda, F. (2012). Do men with eating disorders differ from women in clinics, psychopathology and personality? *European Eating Disorders Review, 20*(1), 23-31. doi:10.1002/erv.1146.

Oberndorfer, T. A., Frank, G. K., Simmons, A. N., Wagner, A., McCurdy, D., Fudge, J. L., Yang, T. T., Paulus, M. P., & Kaye, W. H. (2013). Altered insula response to sweet taste processing after recovery from anorexia and bulimia nervosa. *The American Journal of Psychiatry*, *170*(10), 1143–1151. doi:10.1176/appi.ajp.2013.11111745

O'Brien, K.M. & Vincent, N.K. (2003). Psychiatric comorbidity in anorexia and bulimia nervosa: nature, prevalence, and causal relationships. *Clinical Psychology Review, 23*(1), 57-74. doi:10.1016/S0272-7358(02)00201-5

Office for National Statistics (2016). Disability-Free Life Expectancy by Upper Tier Local Authority: England 2012 to 2014. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/disabilityfreelifeexpectancybyuppertierlocalauthority/england2012to2014

Office for National Statistics (2019a). National life tables, UK: 2016 to 2018. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2016to2018

Office for National Statistics (2019b). Suicides in the UK: 2018 registrations. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesintheunitedkingdom/2018registrations

O'Hara, C.B., Campbell, I.C. & Schmidt, U. (2015). A reward-centred model of anorexia nervosa: A focussed narrative review of the neurological and psychophysiological literature. *Neuroscience & Biobehavioral Reviews, 52*, 131-152. doi:10.1016/j.neubiorev.2015.02.012

Oldershaw, A., Hambrook, D., Stahl, D., Tchanturia, K., Treasure, J. & Schmidt, U. (2010). Emotional Theory of Mind and Emotional Awareness in Recovered Anorexia Nervosa Patients. *Psychological Medicine, 72*(1), 73-79. doi:10.1097/PSY.0b013e3181c6c7ca

Oldershaw, A., Hambrook, D., Stahl, D., Tchanturia, K., Treasure, J. & Schmidt, U. (2011). The socio-emotional processing stream in anorexia nervosa. *Neuroscience and Biobehavioral Reviews, 35*(3), 970-988. doi:10.1016/j.neubiorev.2010.11.001

Oldershaw, A., Treasure, J., Hambrook, D., Tchanturia, K. & Schmidt, U. (2011). Is anorexia nervosa a version of autism spectrum disorders? *European Eating Disorders Review, 19,* 462-474. doi:10.1002/erv.1069

Oldershaw, A., DeJong, H., Hambrook, D., Broadbent, H., Tchanturia, K., Treasure, J. & Schmidt, U. (2012). Emotional processing following recovery from anorexia nervosa. *European Eating Disorders Review, 20*(6), 502-509. doi10.1002/erv.2153

Olmsted, M.P., Davis, R., Garner, D. M., Eagle, M., Rockert, W. & Irvine, M. J. (1991). Efficacy of a brief group psychoeducational intervention for bulimia nervosa. *Behaviour Research and Therapy, 29*(1), 71-83. doi:10.1016/s0005-7967(09)80009-0

Olsavsky, A.K., Shott, M.E., DeGuzman, M.C. & Frank, G.K.W. (2019). Neural correlates of taste reward value across eating disorders. *Psychiatry Research: Neuroimaging, 30*(288), 76-84. doi:10.1016/j.pscychresns.2018.08.010

Ortega, F.J., Aguera, Z., Sabater, M., Moreno-Navarrete, J.M., Alonso-Ledesma, I., Xifra, G., Botas, P., Delgado, E., Jimenez-Murcia, S., Fernandez-Garcia, J., Tinahones, F.J., Banos, R.M., Botella, C., de la Torre, R., Fruhbeck, G., Rodriguez, A., Estivill, X., Casanueva, F., Ricart, W., Fernandez-Aranda, F. & Fernandez-Real, J.M. (2016). Genetic variations of the bitter taste receptor TAS2R38 are associated with obesity and impact on single immune traits. *Molecular Nutrition & Food Research, 60*(7), 1673–1683. doi:10.1002/mnfr.201500804

Ostrolenk, A., Bao, V.A., Mottron, L., Collignon, O. & Bertone, A. (2019). Reduced multisensory facilitation in adolescents and adults on the Autism Spectrum. *Scientific Reports, 9*. doi:10.1038/s41598-019-48413-9

Overberg, J., Hummel, T., Krude, H., & Wiegand, S. (2012). Differences in taste sensitivity between obese and non-obese children and adolescents. *Archives of Disease in Childhood, 97*(12), 1048–1052. doi:10.1136/archdischild-2011-301189

Palmer, R. L., Birchall, H., McGrain, L. & Sullivan, V. (2002). Self-help for bulimic disorders: a randomised controlled trial comparing minimal guidance with face-to-face or telephone guidance. *The British Journal of Psychiatry, 181*, 230-235. doi:10.1192/bjp.181.3.230

Palser, E.R., Fotopoulou, A., Pellicano, E. & Kilner, J.M. (2018). The link between interoceptive processing and anxiety in children diagnosed with autism spectrum disorder: Extending adult findings into a developmental sample. *Biological Psychology, 136*, 13-21. doi:10.1016/j.biopsycho.2018.05.003

Pan, C.Y. (2008). Objectively measured physical activity between children with autism spectrum disorders and children without disabilities during inclusive recess settings in Taiwan. *Journal of Autism and Developmental Disorders, 38*(7), 1292-1301. doi:10.1007/s10803-007-0518-6

Parker, J.D.A., Taylor, G.J. & Bagby, R.M. (2003). The 20-Item Toronto Alexithymia Scale. III. Reliability and factorial validity in a community population. *Journal of Psychosomatic Research, 55*(3), 269-275. doi:10.1016/s0022-3999(02)00578-0

Patil, I., Melsbach, J., Hennig-Fast, K., & Silani, G. (2016). Divergent roles of autistic and alexithymic traits in utilitarian moral judgments in adults with autism. *Scientific Reports, 6*, 23637. doi:10.1038/srep23637

Paulus, M.P. & Stein, M.B. (2006). An insular view of anxiety. *Biological Psychiatry, 60*(4), 383-387. doi:10.1016/j.biopsych.2006.03.042

Paulus, M.P. & Stein, M.B. (2010). Interoception in anxiety and depression. *Brain Structure and Function, 214*, 451-463. doi:10.1007/s00429-010-0258-9

Pellicano, E. & Stears, M. (2011). Bridging autism, science and society: moving toward an ethically informed approach to autism research. *Autism Research, 4*(4), 271-82. doi:10.1002/aur.201

Perko, V.L., Forbush, K.T., Siew, C.S.Q. & Tregarthen, J.P. (2019). Application of network analysis to investigate sex differences in interactive systems of eating-disorder psychopathology. *International Journal of Eating Disorders, 52*(12), 1343-1352. doi:10.1002/eat.23170

Peterson, C.B., Mitchell, J.E., Engbloom, S., Nugent, S., Pederson Mussell, M., Crow, S.J. & Thuras, P. (2001). Self-help versus therapist-led group cognitive-behavioral treatment of binge eating disorder at follow-up. *International Journal of Eating Disorder,s 30*(4), 363-374. doi:10.1002/eat.1098

Peterson, C.B., Mitchell, J.E., Crow, S.J., Crosby, R.D., & Wonderlich, S.A. (2009). The efficacy of self-help group treatment and therapist-led group treatment for binge eating disorder. *The American Journal of Psychiatry*, *166*(12), 1347–1354. doi:10.1176/appi.ajp.2009.09030345

Peterson, C.B., Becker, C.B., Treasure, J., Shafran, R., & Bryant-Waugh, R. (2016). The three-legged stool of evidence-based practice in eating disorder treatment: research, clinical, and patient perspectives. *BMC Medicine*, *14*, 69. doi:10.1186/s12916-016-0615-5

Pettersen, G., Wallin, K. & Bjork, T. (2016). How do males recover from eating disorders? An interview study. *BMJ Open*. doi:10.1136/bmjopen-2015-010760

Pila, E., Mond, J.M., Griffiths, S., Mitchison, D. & Murray, S.B. (2017). A thematic content analysis of #cheatmeal images on social media: Characterizing an emerging dietary trend. *International Journal of Eating Disorders, 50*(6), 698-706. doi:10.1002/eat.22671

Pollatos, O., Kurz, A.L., Albrecht, J., Schreder, T., Kleemann, A.M., Schopf, V., Kopietz, R., Wiesmann, M. & Schandry, R. (2008). Reduced perception of bodily signals in anorexia nervosa. *Eating Behaviours, 9*(4), 381-388. doi:10.1016/j.eatbeh.2008.02.001

Pollatos, O., Herbert, B. M., Berberich, G., Zaudig, M., Krauseneck, T., Tsakiris, M. (2016). Atypical self-focus effect on interoceptive accuracy in Anorexia Nervosa. *Frontiers in Human Neuroscience, 10*, 484. doi:10.3389/fnhum.2016.00484

Pooni, J., Ninteman, A., Bryant-Waugh, R., Nicholls, D. & Mandy, W. (2012). Investigating Autism Spectrum Disorder and Autistic Traits in Early Onset Eating Disorder. *International Journal of Eating Disorders, 45*(4), 583-591. doi:10.1002/eat.20980

Porges, S. (1993). *Body Perception Questionnaire: laboratory of assessment development.* University of Maryland.

Portway, S.M. & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk & Society, 7*(1), 73-83. doi:10.1080/09500830500042086

Postorino, V., Scahill, L., De Peppo, L., Fatta, L. M., Zanna, V., Castiglioni, M.C., Gillespie, S., Vicari, S. & Mazzone, L. (2017). Investigation of Autism Spectrum Disorder and Autistic Traits in an Adolescent Sample with Anorexia Nervosa. *Journal of Autism and Developmental Disorders, 47*(4), 1051-1061. doi:10.1007/s10803-016-3023-y

Poulsen, S., Lunn, S., Daniel, S. I., Folke, S., Mathiesen, B. B., Katznelson, H. & Fairburn, C. G. (2014). A randomized controlled trial of psychoanalytic psychotherapy or cognitive-behavioral therapy for bulimia nervosa. *The American Journal of Psychiatry, 171*(1), 109-116. doi:10.1176/appi.ajp.2013.12121511

Primack, J.M., Addis, M.E., Syzdek, M. & Miller, I.W. (2010). The Men's Stress Workshop: A Gender-Sensitive Treatment for Depressed Men. *Cognitive and Behavioral Practice, 17*(1)*,* 77-87. doi:10.1016/j.cbpra.2009.07.002

Pugliese, C. E., Anthony, L. G., Strang, J. F., Dudley, K., Wallace, G. L., Naiman, D. Q., & Kenworthy, L. (2016). Longitudinal Examination of Adaptive Behavior in Autism Spectrum Disorders: Influence of

Executive Function. *Journal of Autism and Developmental Disorders*, *46*(2), 467–477. doi:10.1007/s10803-015-2584-5

Raevuori, A., Keski-Rahkonen, A. & Hoek, H.W. (2014). A review of eating disorders in males. *Current Opinions in Psychiatry, 27*(6), 426-430. doi:10.1097/YCO.0000000000000113

Raisanen, U., & Hunt, K. (2014). The role of gendered constructions of eating disorders in delayed help-seeking in men: a qualitative interview study. *BMJ Open, (4)*. doi:10.1136/bmjopen-2013-004342.

Rapps, N., Giel, K.E., Sohngen, E., Salini, A., Enck, P., Bischoff, S.C. & Zipfel, S. (2010). Olfactory deficits in patients with anorexia nervosa. *European Eating Disorder Review, 18*(5), 385-89. doi:10.1002/erv.1010.

Rasmussen, M.L., Hjelmeland, H. & Dieserud, G. (2018). Barriers toward help-seeking among young men prior to suicide. *Death Studies, 42*(2), 96-103, doi:10.1080/07481187.2017.1328468

Rastam, M. (2008). Eating disturbances in autism spectrum disorders with focus on adolescent and adult years. *Clinical Neuropsychiatry: Journal of Treatment Evaluation, 5*(1), 31–42.

Redmond, M.L., Galea, S. & Delva, J. (2009). Examining Racial/Ethnic Minority Treatment Experiences with Specialty Behavioral Health Service Providers. *Community Mental Health Journal, 45.* doi:10.1007/s10597-008-9164-5

Rhind, C., Bonfioli, E., Hibbs, R., Goddard, E., Macdonald, P., Gowers, S., Schmidt, U., Tchanturia, K., Micali, N. & Treasure, J. (2014). An examination of autism spectrum traits in adolescents with anorexia nervosa and their parents. *Molecular Autism, 5*. doi:10.1186/2040-2392-5-56

Ricca, V., Castellini, G., Mannucci, E., Lo Sauro, C., Ravaldi, C., Rotella, C.M. & Faravelli, C. (2010). Comparison of individual and group cognitive behavioral therapy for binge eating disorder. A randomized, three-year follow-up study. *Appetite, 55*(3), 656-65. doi:10.1016/j.appet.2010.09.019

Rice, S.M., Telford, N.R., Rickwood, D.J. & Parker, A.G. (2018). Young men's access to community-based mental health care: qualitative analysis of barriers and facilitators*. Journal of Mental Health, 27*(1), 59-65, doi: 10.1080/09638237.2016.1276528

Richard, A., Meule, A., Georgii, C., Voderholzer, U., Cuntz, U., Wilhelm, F. H., & Blechert, J. (2019). Associations between interoceptive sensitivity, intuitive eating, and body mass index in patients with anorexia nervosa and normal-weight controls. *European Eating Disorders Review, 27*(5), 571–577. doi:10.1002/erv.2676

Rieffe, C., Meerum Terwogt, M. & Kotronopoulou, K. (2007). Awareness of Single and Multiple Emotions in High-functioning Children with Autism. *Journal of Autism and Developmental Disorders, 37*, 455-465. doi:10.1007/s10803-006-0171-5

Ring, C. & Brener, J. (2018). Heartbeat counting is unrelated to heartbeat detection: a comparison of methods to quantify interoception. *Psychophysiology, 55*(9), 213084. doi:10.1111/psyp.13084

Ritchie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research. In Burgress, G.R. (Ed). *Analysing Qualitative Data*. London:Routledge, 173-194.

Ritvo, R.A., Ritvo, E.R., Guthrie, D., Ritvo, M.J., Hufnagel, D.H., McMahon, W., Tonge, B., Mataix-Cols, D., Jassi, A., Attwood, T., & Eloff, J. (2011). The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R): a scale to assist the diagnosis of Autism Spectrum Disorder in adults: an international validation study. *Journal of Autism and Developmental Disorders*, *41*(8), 1076–1089. doi:10.1007/s10803-010-1133-5

Riva, G., & Dakanalis, A. (2018). Altered Processing and Integration of Multisensory Bodily Representations and Signals in Eating Disorders: A Possible Path Toward the Understanding of Their Underlying Causes. *Frontiers in Human Neuroscience*, *12*, 49. doi:10.3389/fnhum.2018.00049

Roberts, M., Tchanturia, K. & Treasure, J. (2013). Is attention to detail a similarly strong candidate endophenotype for anorexia nervosa and bulimia nervosa? *The World Journal of Biological Psychiatry, 14*(6), 452-463. doi:10.3109/15622975.2011.639804

Roberts, S. (2012). Boys Will Be Boys… Won't They? Change and Continuities in Contemporary Young Working-class Masculinities. *Sociology, 47*(4). doi:10.1177/0038038512453791

Robertson, C. E. & Baron-Cohen, S. (2017). Sensory perception in autism. *Nature Reviews Neuroscience, 18*, 671-684. doi:10.1038/nrn.2017.112

Robertson, J.M. & Williams, B.W. (2010). "Gender Aware Therapy" for Professional Men in a Day Treatment Center. *Psychotherapy Theory, Research, Practice, Training, 47*(3), 316-326. doi:10.1037/a0021163.

Robinson, K.J., Mountford, V.A. & Sperlinger, D.J. (2012). Being men with eating disorders: Perspectives of male eating disorder service-users. *Journal of Health Psychology, 18*(2), 176-186. doi:10.1177/1359105312440298

Rodin, J., Bartoshuk, L., Peterson, C., & Schank, D. (1990). Bulimia and taste—Possible interactions. *Journal of Abnormal Psychology, 99*(1), 32–39. doi:10.1037/0021-843x.99.1.32

Rolls, E.T. (2007). Sensory processing in the brain related to the control of food intake. *The Proceedings of the Nutrition Society, 66*(1), 96-112. doi:10.1017/S0029665107005332

Rolls, E.T. (2015). Taste, olfactory, and food reward value processing in the brain. *Progress in Neurobiology, 127–128*(Supplement C), 64–90. doi:10.1016/j.pneurobio.2015.03.002

Rosenthal, M., Wallace, G.L., Lawson, R., Wills, M.C., Dixon, E., Yerys, B.E., & Kenworthy, L. (2013). Impairments in real-world executive function increase from childhood to adolescence in autism spectrum disorders. *Neuropsychology*, *27*(1), 13–18. doi:10.1037/a0031299

Rothery, D.J. & Garden, G.M.F. (1988). Anorexia Nervosa and Infantile Autism. *The British Journal of Psychiatry, 153*(5), 714. doi:10.1192/bjp.153.5.714Pu

Rouse, C.H., Jones, G.E. & Kones, J.R. (1988). The effect of body composition and gender on cardiac awareness. *Psychophysiology, 25*(4), 400-407. doi:10.1111/j.1469-8986.1988.tb01876.x

Russell, T.A., Schmidt, U., Doherty, L., Young, V. & Tchanturia, K. (2009). Aspects of social cognition in anorexia nervosa: Affective and cognitive theory of mind. *Psychiatry Research, 168*(3), 181-185. doi:10.1016/j.psychres.2008.10.028

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., Forsyth, K., McCartney, D. & Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism, 20*(5), 628–634. doi:10.1177/1362361315617879

Ruwaard, J., Lange, A., Broeksteeg, J., Renteria-Agirre, A., Schrieken, B., Dolan, C.V. & Emmelkamp, P. (2013). Online cognitive-behavioural treatment of bulimic symptoms: a randomized controlled trial. *Clinical Psychology & Psychotherapy, 20*(4), 308-318. doi:10.1002/cpp.1767

Rynkiewicz, A., Schuller, B., Marchi, E., Piana, S., Camurri, A., Lassalle, A., & Baron-Cohen, S. (2016). An investigation of the 'female camouflage effect' in autism using a computerized ADOS-2 and a test of sex/gender differences. *Molecular Autism, 7*(10). doi:10.1186/s13229-016- 0073-0

Safer, D.L., Robinson, A.H., & Jo, B. (2010). Outcome from a randomized controlled trial of group therapy for binge eating disorder: comparing dialectical behavior therapy adapted for binge eating to an active comparison group therapy. *Behavior Therapy*, *41*(1), 106–120. doi:10.1016/j.beth.2009.01.006

Sagar-Ouriaghli, I., Godfrey, E., Bridge, L., Meade, L., & Brown, J. (2019). Improving Mental Health Service Utilization Among Men: A Systematic Review and Synthesis of Behavior Change Techniques

Within Interventions Targeting Help-Seeking. *American Journal of Men's Health*, *13*(3), 1557988319857009. doi:10.1177/1557988319857009

Samson, A.C., Huber, O., & Gross, J. (2012). Emotion regulation in Asperger's syndrome and high-functioning autism. *Emotion, 12*(4), 659–665. doi:10.1037/a0027975

Sanchez-Ortiz, V.C., Munro, C., Startup, H., Treasure, J. & Schmidt, U. (2011). The Role of Email Guidance in Internet-Based Cognitive-Behavioural Self-Care Treatment for Bulimia Nervosa. *European Eating Disorders Review, 19*, 342-348. doi:10.1002/erv.1074

Saure, E., Laasonen, M., Lepisto-Paisley, T., Mikkola, K., Algars, M. & Raevuori, A. (2020). Characteristics of autism spectrum disorders are associated with longer duration of anorexia nervosa: A systematic review and meta-analysis. *International Journal of Eating Disorders.* doi:10.1002/eat.23259

Schaller, U.M. & Rauh, R. (2017). What Difference Does It Make? Implicit, Explicit and Complex Social Cognition in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 47*, 961-979. doi:10.1007/s10803-016-3008-x

Schandry, R. (1981). Heartbeat perception and emotional experience. *Psychophysiology, 18*(4), 483-488. doi:10.111/j.1469-8986.1981.tb03486.x

Schauder, K.B., Mash, L.E., Bryant, L.K. & Cascio, C.J. (2015). Interoceptive ability and body awareness in autism spectrum disorder. *Journal of Experimental Child Psychology, 131*, 193-200. doi:10.1016/j.jecp.2014.11.002

Schebendach, J.E., Klein, D.A., Mayer, L.E.S., Devlin, M.J., Attia, E., & Walsh, B.T. (2014). Assessment of fat taste in individuals with and without anorexia nervosa. *International Journal of Eating Disorders, 47*(2), 215–218. doi:10.1002/eat.22226

Schecklmann, M., Pfannstiel, C., Fallgatter, A.J., Warnke, A., Gerlach, M. & Romanos, M. (2012). Olfaction in child and adolescent anorexia nervosa. *Journal of Neural Transmission, 119*(6), 721-28. doi:10.1007/s00702-011-0752-0

Schiffman, S.S., & Graham, B.G. (2000). Taste and smell perception affect appetite and immunity in the elderly. *European Journal of Clinical Nutrition, 54*(S3), S54–S63.

Schiffman, S.S. (2018). Influence of medications on taste and smell. *World Journal of Otorhinolaryngology, 4*(1), 84-91. doi:10.1016/j.wjorl.2018.02.005

Schmidt, U. & Treasure, J. (2006). Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology, 45*, 343-366. doi:10.1348/014466505X53902

Schmidt, U., Lee, S., Beecham, J., Perkins, S., Treasure, J., Yi, I., Winn S., Robinson, P., Murphy, R., Keville, S., Johnson-Sabine, E., Jenkins, M., Frost, S., Dodge, L., Berelowitz, M. & Eisler, I. (2007). A randomized controlled trial of family therapy and cognitive behavior therapy guided self-care for adolescents with bulimia nervosa and related disorders. *American Journal of Psychiatry, 164*(4), 591-598. doi:10.1176/ajp.2007.164.4.591

Schmitt, L., Heiss, C.J. & Campbell, E.E. (2008). A Comparison of Nutrient Intake and Eating Behaviors of Boys With and Without Autism. *Topics in Clinical Nutrition, 23*(1), 23-31. doi:10.1097/01.TIN.0000312077.45953.6c

Schneider, K., Regenbogen, C., Pauly, K.D., Gossen, A., Schneider, D.A., Mevissen, L., Michel, T.M., Gur, R.C., Habel, U. & Schneider, F. (2013). Evidence for Gender-Specific Endophenotypes in High-Functioning Autism Spectrum Disorder During Empathy. *Autism Research, 6*(6), 506-521. doi:10.1002/aur.1310

Schreck, K.A., Williams, K. & Smith, A.F. (2004). A Comparison of Eating Behaviors Between Children with and Without Autism. *Journal of Autism and Developmental Disorders, 34*(4), 433-438. doi:10.1023/b:jadd.0000037419.78531.86

Schreder, T., Albrecht, J., Kleemann, A.M., Schopf, V., Kopietz, R., Anzinger, A., Demmel., M., Linn, J., Pollatos, O. & Wiesmann, M. (2008). Olfactory performance of patients with anorexia nervosa and healthy subjects in hunger and satiety. *Rhinology, 46*(3), 175-83.

Schulte-Ruther, M., Mainz, V., Fink, G.R., Herpertz-Dahlmann, B. & Konrad, K. (2012). Theory of Mind and the Brain in Anorexia Nervosa: Relation to Treatment Outcome. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(8), 832-841. doi:10.1016/j.jaac.2012.06.007

Schulz, S.E. & Stevenson, R.A. (2020). Differentiating between sensory sensitivity and sensory reactivity in relation to restricted interests and repetitive behaviours. *Autism, 24*(1). doi:10.1177/1362361319850402

Scott, F. J., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). Brief report - Prevalence of autism spectrum conditions in children aged 5-11 years in Cambridgeshire, UK. *Autism, 6*(3), 231–237. doi:10.1177/1362361302006003002

Sedgewick, F., Leppanen, J. & Tchanturia, K. (2019). Autistic adult outcomes on weight and body mass index: a large-scale online study. *Eating and Weight Disorders*. doi:10.1007/s40519-019-00695-8

Sedgewick, F., Kerr-Gaffney, J., Leppanen, J., & Tchanturia, K. (2019). Anorexia Nervosa, Autism, and the ADOS: How Appropriate Is the New Algorithm in Identifying Cases? *Frontiers in Psychiatry, 10*. doi:10.3389/fpsyt.2019.00507

Seidler, Z.E., Dawes, A.J., Rice, S.M., Oliffe, J.L., Dhillon, H.M. (2016). The role of masculinity in men's help-seeking for depression: A systematic review. *Clinical Psychology Review, 49*, 106-118. doi:10.1016/j.cpr.2016.09.002

Sepulveda, A.R., Lopez, C., Todd, G., Whitaker, W. & Treasure, J. (2008). An Examination of the Impact of "The Maudsley Eating Disorder Collaborative Care Skills Workshops" on the Well Being of Carers: A Pilot Study. *Social Psychiatry and Psychiatric Epidemiology, 43*(7), 584-591. doi:10.1007/s00127-008-0336-y

Shah, P., Hall, R., Catmur, C. & Bird, G. (2016). Alexithymia, not autism, is associated with impaired interoception. *Cortex, 81*, 215-220. doi:10.1016/j.cortex.2016.03.021

Shapiro, J.R., Reba-Harrelson, L., Dymek-Valentine, M., Woolson, S.L., Hamer, R.M. & Bulik, C.M. (2007). Feasibility and acceptability of CD-ROM-based cognitive-behavioural treatment for binge-eating disorder. *European Eating Disorders Review, 15*(3), 175-184. doi:10.1002/erv.787

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family - caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), 7–17. doi:10.5498/wjp.v6.i1.7

Sharp, W.G., Postorino, V., McCracken, C.E., Berry, R.C., Criado, K.K., Burrell, T.L. & Scahill, L. (2018). Dietary Intake, Nutrient Status, and Growth Parameters in Children with Autism Spectrum Disorder and Severe Food Selectivity: An Electronic Medical Record Review. *Journal of the Academy of Nutrition and Dietetics, 118*(10), 1943-1950. doi:10.1016/j.jand.2018.05.005

Sheppard, E., Pillai, D., Wong, G.T., Ropar, D. & Mitchell, P. (2016). How Easy is it to Read the Minds of People with Autism Spectrum Disorder? *Journal of Autism and Developmental Disorders, 46*(4), 1247-54. doi:10.1007/s10803-015-2662-8.

Sifneos, P.E. (1973). The Prevalence of 'Alexithymic' Characteristics in Psychosomatic Patients. *Psychotherapy and Psychosomatics, 22*, 255-262. doi:10.1159/000286529

Silani, G., Bird, G., Brindly, R., Singer, T., Frith, C. & Frith, U. (2008). Levels of emotional awareness and autism: An fMRI study. *Social Neuroscience, 3*(2), 97-112. doi:10.1080/17470910701577020

Simon, Y., Bellisle, F., Monneuse, M.O., Samuel-Lajeunesse, B., & Drewnowski, A. (1993). Taste responsiveness in anorexia-nervosa. *British Journal of Psychiatry, 162*(2), 244–246. doi:10.1192/bjp.162.2.244

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T. & Baird, G. (2008). Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(8), 921-929. doi:10.1097/CHI.0b013e318179964f

Sizoo, B.B., Horwitz, E.H., Teunisse, J.P., Kan, C.C., Vissers, C., Forceville, E., Voorst, A. & Geurts, H.M. (2015). Predictive validity of self-report questionnaires in the assessment of autism spectrum disorders in adults. *Autism, 19*(7), 842-849. doi:10.1177/1362361315589869

Small, D.M., Zatorre, R.J., Dagher, A., Evans, A.C., & Jones-Gotman, M. (2001). Changes in brain activity related to eating chocolate: From pleasure to aversion. *Brain: A Journal of Neurology, 124*(9), 1720–1733. doi:10.1093/brain/124.9.1720

Small, D.M. (2006). Central gustatory processing in humans. *Advances in Oto-Rhino-Laryngology, 63*, 191-220. doi:10.1159/000093761

Small, D.M. (2012). Flavor is in the brain. (2012). *Physiology & Behaviour, 107*(4), 540-552. doi:10.1016/j.physbeh.2012.04.011

Smith, A., Roux, S., Naidoo, N.T. & Venter, D.J.L. (2005). Food choices of tactile defensive children. *Nutrition, 21*(1), 14-9. doi:10.1016/j.nut.2004.09.004

Solmi, F., Bentivegna, F., Bould, H., Mandy, W., Kothari, R., Dheeraj, R., Skuse, D. & Lewis, G. (2020). Trajectories of autistic social traits in childhood and adolescence and disordered eating behaviours at age 14 years: A UK general population cohort study. *The Journal of Child Psychology and Psychiatry*. doi:10.1111/jcpp.13255

Sonneville, K.R. & Lipson, S.K. (2018). Disparities in eating disorder diagnosis and treatment according to weight status, race/ethnicity, socioeconomic background, and sex among college students. *International Journal of Eating Disorders, 51*, 518– 526. doi:10.1002/eat.22846

Sorokowski, P., Karwowski, M., Misiak, M., Marczak, M.K., Dziekan, M., Hummel, T. & Sorokowska, A. (2019). Sex Differences in Human Olfaction: A Meta-Analysis. *Frontiers in Psychology.* doi:10.3389/fpsyg.2019.00242

Spain, D., Sin, J., Chalder, T., Murphy, D. & Happe, F. (2015). Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review. *Research in Autism Spectrum Disorders, 9*, 151-162. doi:10.1016/j.rasd.2014.10.019

Spain, D. & Happe, F. (2020). How to Optimise Cognitive Behaviour Therapy (CBT) for People with Autism Spectrum Disorders (ASD): A Delphi Study. *Journal of Rational-Emotive & Cognitive-Behavior Therapy, 38,* 184-208. doi:10.1007/s10942-019-00335-1

Speranza, M., Loas, G., Wallier, J. & Corcos, M. (2007). Predictive Value of Alexithymia in Patients With Eating Disorders: A 3-year Prospective Study. *Journal of Psychosomatic Research, 63*(4), 365-371. doi:10.1016/j.jpsychores.2007.03.008

Spielberger, C.D. (1983). *State-Trait Anxiety Inventory (Form Y) Manual*. Mind Garden/California.

Srivastava, A. & Thomson, S.B. (2009). Framework Analysis: A Qualitative Methodology for Applied Policy Research. *Journal of Administration and Governance, 4*(2).

Stanford, S.C. & Lemberg, R. (2012). Measuring Eating Disorders in Men: Development of the Eating Disorder Assessment for Men (EDAM). *Eating Disorders, 20*(5), 427-436. doi:10.1080/10640266.2012.715522

Steele, A. L. & Wade, T.D. (2008). A randomised trial investigating guided self-help to reduce perfectionism and its impact on bulimia nervosa: a pilot study. *Behaviour Research and Therapy, 46*(12), 1316-1323. doi:10.1016/j.brat.2008.09.006

Steiner, J.E., Glaser, D., Hawilo, M.E., & Berridge, K C. (2001). Comparative expression of hedonic impact: Affective reactions to taste by human infants and other primates. *Neuroscience & Biobehavioral Reviews, 25*(1), 53–74. doi:10.1016/S0149-7634(00)00051-8

Steinhausen, H. C. (2009). Outcome of Eating Disorders. *Child and Adolescent Psychiatric Clinics of North America, 18*(1), 225-242. doi:10.1016/j.chc.2008.07.013

Stewart, C. S., McEwen, F. S., Konstantellou, A., Eisler, I. & Simic, M. (2017). Impact of ASD traits on treatment outcomes of eating disorders in girls. *European Eating Disorders Review, 25*(2), 123-128. doi: 10.1002/erv.249

Stice, E., Marti, C. N., & Rohde, P. (2013). Prevalence, incidence, impairment, and course of the proposed DSM-5 eating disorder diagnoses in an 8-year prospective community study of young women. *Journal of Abnormal Psychology, 122*(2), 445–457. doi:10.1037/a0030679

Strang, J. F., Kenworthy, L., Daniolos, P., Case, L., Wills, M. C., Martin, A., & Wallace, G. L. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research in Autism Spectrum Disorders, 6*(1), 406–412. doi:10.1016/j.rasd.2011.06.015

Striegel, R.H., Bedrosian, R., Wang, C. & Schwartz, S. (2012). Why men should be included in research on binge eating: Results from a comparison of psychosocial impairment in men and women. *International Journal of Eating Disorders, 45*, 233-240. doi:10.1002/eat.20962

Striegel-Moore, R.H., Garvin, V., Dohm, F.A. & Rosenheck, R.A. (1999). Psychiatric comorbidity of eating disorders in men: a national study of hospitalized veterans. *International Journal of Eating Disorders, 25*(4), 399-404. doi:10.1002/(sici)1098-108x(199905)25:4<399::aid-eat4>3.0.co;2-0.

Striegel-Moore, R.H., Leslie, D., Petrill, S. A., Garvin, V. & Rosenheck, R.A. (2000). One-year use and cost of inpatient and outpatient services among female and male patients with an eating disorder: evidence from a national database of health insurance claims. *International Journal of Eating Disorders, 27*(4), 381-9. doi:10.1002/(sici)1098-108x(200005)27:4

Striegel-Moore, R.H., Wilson, G.T., DeBar, L., Perrin, N., Lynch, F., Rosselli, F., & Kraemer, H.C. (2010). Cognitive behavioral guided self-help for the treatment of recurrent binge eating. *Journal of Consulting and Clinical Psychology*, *78*(3), 312–321. doi:10.1037/a0018915

Strobel, C., Quadflieg, N., Voderholzer, U., Naab, S. & Fichter, M. (2018). Short- and long-term outcome of males treated for anorexia nervosa: A review of the literature. *Eating and Weight Disorders 23*, 541-552. doi:10.1007/s40519-018-0538-6

Strober, M., Freeman, R., Lampert, C., Diamond, J., Teplinksy, C. & DeAntonio, M. (2006). Are there gender differences in core symptoms, temperament, and short-term prospective outcome in anorexia nervosa? *International Journal of Eating Disorders, 39*(7), 570-575. doi:10.1002/eat.20293

Strother, E., Lemberg, R., Stanford, S. C., & Turberville, D. (2012). Eating disorders in men: underdiagnosed, undertreated, and misunderstood. *Eating Disorders, 20*(5), 346–355. doi:10.1080/10640266.2012.715512

Stoving, R.K., Andries, A., Brixen, K., Bilenberg, N. & Horder, K. (2011). Gender differences in outcome of eating disorders: A retrospective cohort study. *Psychiatry Research, 186*(2-3), 362-366. doi:10.1016/j.psychres.2010.08.005

Sunday, S.R. & Halmi, K.A. (1990). Taste perceptions and hedonics in eating disorders. *Physiology & Behaviour, 48*(5), 587-94. doi:10.1016/0031-9384(90)90196-b

Sweeting, H., Walker, L., MacLean, A., Patterson, C., Raisanen, U., & Hunt, K. (2015). Prevalence of eating disorders in males: a review of rates reported in academic research and UK mass media. *International Journal of Men's Health*, *14*(2). doi:10.3149/jmh.1402.86.

Swift, L., Stephenson, R. & Royce, J. (2006). The 20-item Toronto Alexithymia Scale: Validation of Factor Solutions Using Confirmatory Factor Analysis on Physiotherapy Out-Patients. *Psychology and Psychotherapy, 79*, 83-88. doi:10.1348/147608305X42875

Swinbourne, J., Hunt, C., Abbott, M., Russell, J., St Clare, T. & Touyz, S. (2012). The comorbidity between eating disorders and anxiety disorders: prevalence in an eating disorder sample and anxiety disorder sample. *The Australian and New Zealand Journal of Psychiatry, 46*(2), 118-131. doi:10.1177/0004867411432071.

Sysko, R. & Walsh, T. (2008). A critical evaluation of the efficacy of self-help interventions for the treatment of bulimia nervosa, and binge- eating disorder. *International Journal of Eating Disorders, 41*(2), 97-112. doi:10.1102/eat

Syzdek, M.R., Addis, M.E., Green, J.D., Whorley, M.R., & Berger, J. (2014). A Pilot Trial of Gender-Based Motivational Interviewing for Help-Seeking and Internalizing Symptoms in Men. *Psychology of Men & Masculinity*, *15*(1), 90–94. doi:10.1037/a0030950

Syzdek, M.R., Green, J.D., Lindgren, B.R., & Addis, M.E. (2016). Pilot trial of gender-based motivational interviewing for increasing mental health service use in college men. *Psychotherapy, 53*(1), 124–129. doi:10.1037/pst0000043

Szalay, C., Abraham, I., Papp, S., Takacs, G., Lukats, B., Gati, A., & Karadi, Z. (2010). Taste reactivity deficit in anorexia nervosa. *Psychiatry & Clinical Neurosciences, 64*(4), 403–407. doi:10.1111/j. 1440-1819.2010.02106.x

Tani, P., Lindberg, N., Joukamaa, M., Nieminen-von Wendt, T., von Wendt, L., Appelberg, B., Rimon, R. & Porkka-Heiskanen, T. (2004). Asperger Syndrome, Alexithymia and Perception of Sleep. *Neuropsychobiology, 49*(2), 64-70. doi:10.1159/000076412

Tavassoli, T. & Baron-Cohen, S. (2012). Taste Identification in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders, 42*, 1419-1424. doi:10.1007/s10803-011-1377-8

Tavassoli, T., Hoekstra, R.A. & Baron-Cohen, S. (2014). The Sensory Perception Quotient (SPQ): development and validation of a new sensory questionnaire for adults with and without autism. *Molecular Autism, 5*, 29. doi:10.1186/2040-2392-5-29

Tavassoli, T., Miller, L.J., Schoen, S.A., Nielsen, D.M. & Baron-Cohen-S. (2014). Sensory over-responsivity in adults with autism spectrum conditions. *Autism, 18*(4), 428-432. doi:10.1177/1362361313477246

Tavassoli, T., Bellesheim, K., Siper, P.M., Wang, A.T., Halpern, D., Gorenstein, M., Grodberg, D., Kolevzon, A. & Buxbaum, J. (2016). Measuring Sensory Reactivity in Autism Spectrum Disorder: Application and Simplification of a Clinician-Administered Sensory Observation Scale. *Journal of Autism and Developmental Disorders, 46*(1), 287-293. doi: 10.1007/s10803-015-2578-3

Taylor, B., Jick, H. & MacLaughlin, D. (2013). Prevalence and incidence rates of autism in the UK: time trend from 2004–2010 in children aged 8 years. *BMJ Open, 3*(10). doi:10.1136/bmjopen-2013-003219

Tchanturia, K., Happe, F., Godley, J., Treasure, J., Bara-Carril, N. & Schmidt, U. (2004). 'Theory of mind' in anorexia nervosa. *European Eating Disorders Review, 12*(6), 361-366. doi:10.1002/erv.608

Tchanturia, K., Davies, H., Harrison, A., Fox, J.R.E., Treasure, J. & Schmidt, U. (2012). Altered social hedonic processing in eating disorders. *International Journal of Eating Disorders, 45*(8), 962-969. doi:10.1002/eat.22032

Tchanturia, K., Davies, H., Roberts, M., Harrison, A., Nakazato, M., Schmidt, U., Treasure, J., & Morris, R. (2012). Poor cognitive flexibility in eating disorders: examining the evidence using the Wisconsin Card Sorting Task. *PloS One*, *7*(1), e28331. doi:10.1371/journal.pone.0028331

Tchanturia, K., Smith, E., Weineck, F., Fidanboylu, E., Kern, N., Treasure, J. & Baron-Cohen, S. (2013). Exploring autistic traits in anorexia nervosa: a clinical study. *Molecular Autism, 4*. doi:10.1186/2040-2392-4-44

Tchanturia, K., Lounes, N. & Holttum, S. (2014). Cognitive remediation in anorexia nervosa and related conditions: a systematic review. *European Eating Disorders Review, 22*(6), 454-62. doi:10.1002/erv.2326

Tchanturia, K., Doris, E., Mountford, V. & Fleming, C. (2015). Cognitive remediation and emotion skills training (CREST) for anorexia nervosa in individual format: self-reported outcomes. *BMC Psychiatry, 15*, 53. doi:10.1186/s12888-015-0434-9

Tchanturia, K., Larsson, E., & Adamson, J. (2016). How anorexia nervosa patients with high and low autistic traits respond to group Cognitive Remediation Therapy. *BMC Psychiatry*, *16*(1), 334. doi:10.1186/s12888-016-1044-x

Tchanturia, K., Larsson, E., & Brown, A. (2016). Benefits of group cognitive remediation therapy in anorexia nervosa: case series. *Neuropsychiatrie : Klinik, Diagnostik, Therapie und Rehabilitation : Organ der Gesellschaft Osterreichischer Nervenarzte und Psychiater, 30*(1), 42–49. doi:10.1007/s40211-016-0177-y

Tchanturia, K., Adamson, J., Leppanen, J. & Westwood, H. (2019). Characteristics of autism spectrum disorder in anorexia nervosa: A naturalistic study in an inpatient treatment programme. *Autism, 23*(1), 123-130. doi:10.1177/1362361317722431

Telch, C.F., Agras, W.S., Rossiter, E.M., Wifley, D. & Kenardy, J. (1990). Group cognitive-behavioral treatment for the nonpurging bulimic: an initial evaluation. *Journal of Consulting and Clinical Psychology, 58*(5), 629-635. doi:10.1037//0022-006x.58.5.629

Tenconi, E., Santonastaso, P., Deortes, D., Bosello, R., Titton, F., Mapelli, D. & Favaro, A. (2010). Set-shifting abilities, central coherence, and handedness in anorexia nervosa patients, their unaffected siblings and healthy controls: Exploring putative endophenotypes. *The World Journal of Biological Psychiatry, 11*(6), 813-823. doi:10.3109/15622975.2010.483250

Tepper, B. J., Banni, S., Melis, M., Crnjar, R., & Tomassini Barbarossa, I. (2014). Genetic sensitivity to the bitter taste of 6-n-propylthiouracil (PROP) and its association with physiological mechanisms controlling body mass index (BMI). *Nutrients, 6*(9), 3363–3381. doi:10.3390/nu6093363

Thackwray, D. E., Smith, M. C., Bodfish, J. W., & Meyers, A. W. (1993). A comparison of behavioral and cognitive-behavioral interventions for bulimia nervosa. *Journal of Consulting and Clinical Psychology, 61*(4), 639–645. doi:10.1037/0022-006X.61.4.639

Thapliyal, P. & Hay, P.J. (2014). Treatment experiences of males with an eating disorder: a systematic review of qualitative studies. *Translational Developmental Psychiatry, 2*(1). doi:10.3402/tdp.v2.25552

Thapliyal, P., Mitchison, D. & Hay, P. (2017). Insights into the Experiences of Treatment for An Eating Disorder in Men: A Qualitative Study of Autobiographies. *Behavioral Sciences, 7*(2), 38. doi:10.3390/bs7020038

Thapliyal, P., Mitchison, D., Miller, C., Bowden, J., Gonzalez-Chica, D.A., Stocks, N., Touyz, S. & Hay, P. (2017). Comparison of mental health treatment status and use of antidepressants in men and women with eating disorders. *Eating Disorders, 26*(3), 248-262. doi:10.1080/10640266.2017.1383788

Thomas, P.R. (1994). Anorexia Nervosa in People with Severe Learning Disabilities. *British Journal of Learning Disabilities, 22*(1), 25-26. doi:10.1111/j.1468-3156.1994.tb00108.x

Thompson-Brenner, H., Shingleton, R. M., Thompson, D. R., Satir, D. A., Richards, L. K., Pratt, E. M. & Barlow, D. H. (2016). Focused vs. Broad enhanced cognitive behavioral therapy for bulimia nervosa with comorbid borderline personality: A randomized controlled trial. *International Journal of Eating Disorders, 49*(1), 36-49. doi:10.1002/eat.22468

Tierney, S., Burns, J. & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spectrum. *Research in Autism Spectrum Disorders, 23*, 73-83. doi:10.1016/j.rasd.2015.11.013

Till, C. (2011). The quantification of gender: Anorexia nervosa and femininity. *Health Sociology Review*, *20*(4), 437-449. doi:10.5172/hesr.2011.20.4.437

Tint, A. & Weiss, J.A. (2018). A qualitative study of the service experiences of women with autism spectrum disorder. *Autism, 22*(8), 928-937. doi:10.1177/1362361317702561

Titova, O.E., Hjorth, O.C., Schiöth, H.B., & Brooks, S.J. (2013). Anorexia nervosa is linked to reduced brain structure in reward and somatosensory regions: a meta-analysis of VBM studies. *BMC Psychiatry*, *13*, 110. doi:10.1186/1471-244X-13-110

Tomchek, S.D., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the Short Sensory Profile. *American Journal of Occupational Therapy, 61*, 190–200.

Tonacci, A., Billeci, L., Tartarisco, G., Ruta, L., Muratori, F., Pioggia, G. & Gangemi, S. (2017). Olfaction in autism spectrum disorders: a systematic review. *Child Neuropsychology, 23*(1), 1-25. doi:10.1080/09297049.2015.1081678

Tonacci, A., Calderoni, S., Billeci, L., Maestro, S., Fantozzi, P., Ciuccoli, F., Morales, M.A., Narzisi, A. & Muratori, F. (2019). Autistic Traits Impact on Olfactory Processing in Adolescent Girls With Anorexia Nervosa Restricting Type. *Psychiatry Research, 274*, 20-26. doi:10.1016/j.psychres.2019.02.026

Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32- item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. doi:10.1093/intqhc/mzm042

Toth, E., Tury, F., Gati, A., Weisz, J., Kondakor, I., & Molnar, M. (2004). Effects of sweet and bitter gustatory stimuli in anorexia nervosa on EEG frequency spectra*. International Journal of Psychophysiology, 52*(3), 285–290. doi:10.1016/j.ijpsycho.2003.11.001

Treasure, J., Schmidt, U., Troop, N., Tiller, J., Todd, G., Keilen, M., & Dodge, E. (1994). First step in managing bulimia nervosa: controlled trial of therapeutic manual. *BMJ (Clinical research ed.)*, *308*(6930), 686–689. doi:10.1136/bmj.308.6930.686

Treasure, J. (2013). Coherence and other autistic spectrum traits and eating disorders: Building from mechanism to treatment. The Birgit Olsson lecture. *Nordic Journal of Psychiatry, 67*(1), 38-42, doi:10.3109/08039488.2012.674554

Treasure, J. & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders, 1*(13). doi:10.1186/2050-2974-1-13

Treasure, J., Willmott, D., Ambwani, S., Cardi, V., Bryan, D. C., Rowlands, K. & Schmidt, U. (2020). Cognitive Interpersonal Model for Anorexia Nervosa Revisited: The Perpetuating Factors that Contribute to the Development of the Severe and Enduring Illness. *Journal of Clinical Medicine, 9*(3). doi:10.3390/jcm9030630.

Trevisan, D. A., Altschuler, M. R., Bagdasarov, A., Carlos, C., Duan, S., Hamo, E., Kala, S., McNair, M. L., Parker, T., Stahl, D., Winkelman, T., Zhou, M., & McPartland, J. C. (2019). A meta-analysis on the relationship between interoceptive awareness and alexithymia: Distinguishing interoceptive accuracy and sensibility. *Journal of Abnormal Psychology, 128*(8), 765–776. doi:10.1037/abn0000454

Udo, T., & Grilo, C.M. (2018). Prevalence and Correlates of DSM-5-Defined Eating Disorders in a Nationally Representative Sample of U.S. Adults. *Biological Psychiatry*, *84*(5), 345–354. doi:10.1016/j.biopsych.2018.03.014

Uljarevic, M. & Hamilton, A. (2012). Recognition of Emotions in Autism: A Formal Meta-Analysis. *Journal of Autism and Developmental Disorders, 43*, 1517-1526. doi:10.1007/s10803-012-1695-5

Vagni, D., Moscone, D., Travaglione, S. & Cotugno, A. (2016). Using the Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) disentangle the heterogeneity of autistic traits in an Italian eating disorder population. *Research in Autism Spectrum Disorders, 32*, 143-155. doi:10.1016/j.rasd.2016.10.002

Vall, E. & Wade, T.D. (2015). Predictors of treatment outcome in individuals with eating disorders: A systematic review and meta-analysis. *International Journal of Eating Disorders, 48*(7), 946-971. doi:10.1002/eat.22411

Van der Velde, J., Servaas, M.N., Goerlich, K.S., Bruggeman, R., Horton, P., Costafreda, S.G. & Aleman, A. (2013). Neural correlates of alexithymia: A meta-analysis of emotion processing studies. *Neuroscience & Biobehavioral Reviews, 37*(8), 1774-1785. doi:10.1016/j.neubiorev.2013.07.008

Van Dongen, M.V., van den Berg, M.C., Vink, N., Kok, F.J., & de Graaf, C. (2012). Taste–nutrient relationships in commonly consumed foods. *British Journal of Nutrition, 108*(1), 140–147. doi:10.1017/S0007114511005277

Vissoker, R.E., Latzer, Y. & Gal, E. (2015). Eating and feeding problems and gastrointestinal dysfunction in Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 12*, 10-21. doi:10.1016/j.rasd.2014.12.010 P

Vivanti, G. (2019). Ask the Editor: What is the Most Appropriate Way to Talk About Individuals with a Diagnosis of Autism? *Journal of Autism and Developmental Disorders, 50*, 691-693. doi:10.1007/s10803-019-04280-x

Vo, M., Lau, J. & Rubinstein, M. (2016). Eating Disorders in Adolescent and Young Adult Males: Presenting Characteristics. *Journal of Adolescent Health, 59*(4), 397-400. doi:10.1016/j.jadohealth.2016.04.005

Vogan, V., Lake, J.K., Tint, A., Weiss, J.A. & Lunksy, Y. (2017). Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal, 10*(2), 264-270. doi:10.1016/j.dhjo.2016.11.002

Volpe, U., Tortorella, A., Manchia, M., Monteleone, A.M., Albert, U. & Monteleone, P. (2016). Eating disorders: What age at onset? *Psychiatry Research, 30*(238), 225-227. doi:10.1016/j.psychres.2016.02.048

Vorst, H.C.M. & Bermond, B. (2001). Validity and reliability of the Bermond–Vorst Alexithymia Questionnaire. *Personality and Individual Differences, 30*(3), 413-434. doi:10.1016/S0191-8869(00)00033-7

Wagner, A., Aizenstein, H., Mazurkewicz, L., Fudge, J., Frank, G.K., Putnam, K., Bailer, U.F., Fischer, L. & Kaye, W.H. (2008). Altered Insula Response to Taste Stimuli in Individuals Recovered from Restricting-Type Anorexia Nervosa. *Neuropsychopharmacology, 33*, 513-523. doi:10.1038/sj.npp.1301443

Wagner, G., Penelo, E., Nobis, G., Mayerhofer, A., Schau, J., Spitzer, M, Imgart, H. & Karwautz, A. (2013). Is technology assisted guided self-help successful in treating female adolescents with bulimia nervosa? *Neuropsychiatrie, 27*(2), 66-73. doi:10.1007/s40211-013-0062-x

Wallace, G.L., Kenworthy, L., Pugliese, C.E., Popal. H.S., White, E.I., Brodsky, E. & Martin, A. (2016). Real-World Executive Functions in Adults with Autism Spectrum Disorder: Profiles of Impairment and Associations with Adaptive Functioning and Co-morbid Anxiety and Depression. *Journal of Autism and Developmental Disorders, 46*, 1071-1083. doi:10.1007/s10803-015-2655-7

Walsh, B.T., Fairburn, C.G., Mickley, D., Sysko, R. & Parides, M. K. (2004). Treatment of bulimia nervosa in a primary care setting. *American Journal of Psychiatry, 161*(3), 556-61. doi:10.1176/appi.ajp.161.3.556

Walters, S., Loads, M. & Russell, A. (2016). A Systematic Review of Effective Modifications to Cognitive Behavioural Therapy for Young People with Autism Spectrum Disorders. *Review Journal of Autism and Developmental Disorders, 3*(2), 137-153. doi:10.1007/s40489-016-0072-2

Watson, H., & Bulik, C. (2013). Update on the treatment of anorexia nervosa: Review of clinical trials, practice guidelines and emerging interventions. *Psychological Medicine*, 43(12), 2477-2500. doi:10.1017/S0033291712002620

Welch, E., Ghaderi, A. & Swenne, I. (2015). A comparison of clinical characteristics between adolescent males and females with eating disorders. *BMC Psychiatry, 15*(45). doi:10.1186/s12888-015-0419-8.

Weltzin, T.E., Cornella-Carlson, T., Fitzpatrick, M.E., Kennington, B., Bean, P. & Jefferies, C. (2012). Treatment Issues and Outcomes for Males With Eating Disorders. *Eating Disorders, 20*(5), 444-459. doi:10.1080/10640266.2012.715527

Wentz, E., Lacey, J.H., Waller, G., Rastam, M., Turk, J. & Gillberg, C. (2005). Childhood Onset Neuropsychiatric Disorders in Adult Eating Disorder Patients. A Pilot Study. *European Child & Adolescent Psychiatry, 14*(8), 431-437. doi:10.1007/s00787-005-0494-3

Wentz, E., Gillberg, I. C., Anckarsater, H., Gillberg, C., Rastam, M. (2009). Adolescent-onset anorexia nervosa: 18 year outcome. *British Journal of Psychiatry, 194*(2), 168-74. doi:10.1192/bjp.bp.107.048686

Westwood, H., Lawrence, V., Fleming, C. & Tchanturia, K. (2016) Exploration of Friendship Experiences, before and after Illness Onset in Females with Anorexia Nervosa: A Qualitative Study. *PLOS One, 11*(9): e0163528. doi:10.1371/journal.pone.0163528

Westwood, H., Stahl, D., Mandy, W., & Tchanturia, K. (2016). The set-shifting profiles of anorexia nervosa and autism spectrum disorder using the Wisconsin Card Sorting Test: A systematic review and meta-analysis. *Psychological Medicine, 46*(9), 1809-1827. doi:10.1017/S0033291716000581

Westwood, H., Eisler, I., Mandy, W., Leppanen, J., Treasure, J. & Tchanturia, K. (2016). Using the Autism-Spectrum Quotient to Measure Autistic Traits in Anorexia Nervosa: A Systematic Review and Meta-Analysis. *Journal of Autism and Developmental Disorders, 46*(3), 964-977. doi:10.1007/s10803-015-2641-0

Westwood, H., Kerr-Gaffney, J., Stahl, D. & Tchanturia, K. (2017). Alexithymia in eating disorders: Systematic review and meta-analyses of studies using the Toronto Alexithymia Scale. *Journal of Psychosomatic Research, 99*, 66-81. doi:10.1016/j.jpsychores.2017.06.007

Westwood, H., Mandy, W. & Tchanturia, K. (2017a). Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Molecular Autism, 16*, 8-12. doi:10.1186/s13229-017-0128-x

Westwood, H., Mandy, W., & Tchanturia, K. (2017b). The association between symptoms of autism and neuropsychological performance in females with Anorexia Nervosa. *Psychiatry Research, 258*, 531-537. doi:10.1016/j.psychres.2017.09.005

Westwood, H., Mandy, W., Simic, M. & Tchanturia, K. (2017). Assessing ASD in Adolescent Females with Anorexia Nervosa using Clinical and Developmental Measures: a Preliminary Investigation. *Journal of Abnormal Child Psychology, 46*, 183-192. doi:10.1007/s10802-017-0301-x

Westwood, H. & Tchanturia, K. (2017). Autism Spectrum Disorder in Anorexia Nervosa: An Updated Literature Review. *Current Psychiatry Reports, 19*(7), 41. doi:10.1007/s11920-017-0791-9

Whaley, A. L., & Davis, K. E. (2007). Cultural competence and evidence-based practice in mental health services: A complementary perspective. *American Psychologist, 62*(6), 563–574. doi:10.1037/0003-066X.62.6.563

White, S.W., Oswald, D., Ollendick, T. & Scahill, L. Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review, 29*(3), 216-229. doi:10.1016/j.cpr.2009.01.003

Whitney, J., Murphy, T., Landau, S., Gavan, K., Todd, G., Whitaker, W. & Treasure, J. (2012), A Practical Comparison of Two Types of Family Intervention: An Exploratory RCT of Family Day Workshops and Individual Family Work as a Supplement to Inpatient Care for Adults with Anorexia Nervosa. *European Eating Disorders Review, 20,* 142-150. doi:10.1002/erv.1076

Wigham, S., Barton, S., Parr, J.R. & Rodgers, J. (2017). A Systematic Review of the Rates of Depression in Children and Adults With High-Functioning Autism Spectrum Disorder. *Journal of*

Mental Health Research in Intellectual Disabilities, 10(4), 267-287. doi:10.1080/19315864.2017.1299267

Wilfley, D.E., Agras, W.S., Telch, C.F., Rossiter, E.M., Schneider, J.A., Cole, A.G., Sifford, L.A. & Raeburn, S.D. (1993). Group cognitive-behavioral therapy and group interpersonal psychotherapy for the nonpurging bulimic individual: a controlled comparison. *Journal of Consulting and Clinical Psychology, 61*(2), 296-305. doi:10.1037//0022-006x.61.2.296

Wilfley, D.E., Welch, R.R., Stein, R.I., Spurrell, E.B., Cohen, L.R., Saelens, B.E., Zoler Dounchis, J., Frank, M.A., Wiseman, C.V. & Matt, G.E. (2002). A randomized comparison of group cognitive-behavioral therapy and group interpersonal psychotherapy for the treatment of overweight individuals with binge-eating disorder. *Archives of General Psychiatry, 59*(8), 713-721. doi:10.1001/archpsyc.59.8.713

Williams, P. G., Dalrymple, N. & Neal, J. (2000). Eating habits of children with autism. *Pediatric Nursing, 26*(3), 259-264.

Willig, C. (2013). *Introducing Qualitative Research in Psychology (Third Edition)*. Berkshire, England: Open University Press.

Wilson, G.T., Eldredge, K.L., Smith, D. & Niles, B. (1991). Cognitive-behavioural treatment with and without response prevention for bulimia. *Behavioural Research and Therapy, 29*(6), 575-583. doi:10.1016/0005-7967(91)90007-p

Wilson, G.T., Wilfley, D.E., Agras, W.S., & Bryson, S.W. (2010). Psychological treatments of binge eating disorder. *Archives of General Psychiatry, 67*(1), 94–101. doi:10.1001/archgenpsychiatry.2009.170

Wittkamp, M.F., Bertsch, K., Vogele, C. & Schulz, A. (2018). A latent state-trait analysis of interoceptive accuracy. *Psychophysiology, 55*(6), e13055. doi:10.1111/psyp.13055

Wockel, L., Hummel, T., Zepf, F. D., Jacob, A., & Poustka, F. (2007). Changed taste perception in patients with eating disorders. *Zeitschrift fur Kinder-& Jugendpsychiatrie & Psychotherapie, 35*(6), 423–434. doi:10.1024/1422-4917.35.6.423

Wockel, L., Jacob, A., Holtmann, M., & Poustka, F. (2008). Reduced number of taste papillae in patients with eating disorders. *Journal of Neural Transmission, 115*(3), 537–544. doi10.1007/s00702-007-0845-y

Wolf, E.M. & Crowther, J.H. (1992). An evaluation of behavioral and cognitive-behavioral group interventions for the treatment of bulimia nervosa in women. *International Journal of Eating Disorders, 11,* 3-15. doi:10.1002/1098-108X(199201)11:1<3::AID-EAT2260110103>3.0.CO;2-V

World Health Organisation. (2010). *Health Impact Assessment: Glossary of Terms Used*. Retrieved from https://www.who.int/hia/about/glos/en/index1.html.

World Health Organisation (2018). *Obesity and Overweight Fact Sheet*. Retrived from http://www.who.int/news-room/fact-sheets/detail/obesity-and-overweight.

Wonderlich, S.A., Mitchell., J.E., Crosby, R.D., Cook Myers, T., Kadlec, K., Lahaise, K., Swan-Kremeier, L., Dokken, J., Lange, M., Dinkel, J., Jorgensen, M. & Schander, L. (2012). Minimizing and Treating Chronicity in the Eating Disorders: A Clinical Overview. *International Journal of Eating Disorders, 45*(4), 467-475. doi:10.1002/eat.20978

Wonderlich, S.A., Peterson, C.B., Crosby, R.D., Smith, T.L., Klein, M.H., Mitchell, J.E. & Crow, S.J. (2014). A randomized controlled comparison of integrative cognitive-affective therapy (ICAT) and enhanced cognitive-behavioural therapy (CBT-E) for bulimia nervosa. *Psychological Medicine, 44*(3), 543-53. doi:10.1017/S0033291713001098

Wong, Y.J., Ho, M.H.R., Wang, S.Y., & Miller, I.S.K. (2017). Meta-analyses of the relationship between conformity to masculine norms and mental health-related outcomes. *Journal of Counseling Psychology, 64*(1), 80–93. doi:10.1037/cou0000176

Woodside, D.B., Garner, D.M., Rockert, W. & Garfinkel, P.E. (1990). Eating Disorders in Males: Insights from a Clinical and Psychometric Comparison with Female patients. In Andersen A.E. (Ed.), *Males with Eating Disorders* (pp. 100-115). Brunner/Mazel.

Woodside, D.B., Garfinkel, P.E., Lin, E., Goering, P., Kaplan, A.S., Goldbloom, D.S. & Kennedy, S.H. (2001). Comparisons of men with full or partial eating disorders, men without eating disorders, and women with eating disorders in the community. *American Journal of Psychiatry, 158*(4), 570-574. doi:10.1176/appi.ajp.158.4.570

Woodward, A. & Kawachi, I. (2000). Why reduce health inequalities? *Journal of Epidemiology & Community Health, 54*(12), 923-929. doi:10.1136/jech.54.12.923

Wright, R., Riedel, R., Sechrest, L., Lane, R.D. & Smith, R. (2018). Sex differences in emotion recognition ability: The mediating role of trait emotional awareness. *Motivation and Emotion, 42*, 149-160. doi:10.1007/s11031-017-9648-0

Yoshida, R., Shin, M., Yasumatsu, K., Takai, S., Inoue, M., Shigemura, N., Takiguchi, S., Nakamura, S. & Ninomiya, Y. (2017). The role of cholecystokinin in peripheral taste signaling in mice. *Frontiers in Physiology, 8*(866). doi:10.3389/fphys.2017.00866

Zamariola, G., Vleminex, E., Corneille, O. & Luminet, O. (2018). Relationship between interoceptive accuracy, interoceptive sensibility, and alexithymia. *Personality and Individual Differences, 125*, 14-20. doi:10.1016/j.paid.2017.12.024

Zigmond, A.S. & Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-70. doi:10.1111/j.1600-0447.1983.tb09716.x

Zipfel, S., Wilde, B., Grob, G., Friederich, H.C., Teufel, M., Schellberg, D., Giel, K.E., de Zwaan, M., Dinkel, A., Herpetz, S., Burgmer, M., Lowe, B., Tagay, S., von Witersheim, J., Zeeck, A., Schade-Brittinger, C., Schauenburg, H., Herzog, W. & ANTOP study group. (2014). Focal psychodynamic therapy, cognitive behaviour therapy, and optimised treatment as usual in outpatients with anorexia nervosa (ANTOP study): randomised controlled trial. *The Lancet, 383*(9912), 127-137. doi:10.1016/S0140-6736(13)61746-8

Zucker, N.L., Merwin, R.M., Bulik, C.M., Moskovich, A., Wildes, J., Groh, J. (2013). Subjective Experience of Sensation in Anorexia Nervosa. *Behavioural Research and Therapy, 51*(6), 256-265. doi:10.1016/j.brat.2013.01.010

Appendices

Appendix A: Ethical Approval Letters

The qualitative approval letter is presented first, followed by the sensory experimental approval.

NHS
Health Research Authority

London - City & East Research Ethics Committee
Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048033/53

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

12 February 2018

Ms Emma Kinnaird
Section of Eating Disorders, Psychological Medicine
103 Denmark Hill
Institute of Psychiatry, Psychology and Neuroscience, King's College London
SE5 8AF

Dear Ms Kinnaird

Study title:	**Beyond the stereotypes: characterising the unique features of under-researched eating disorder populations, and implications for treatment**
REC reference:	**18/LO/0050**
IRAS project ID:	**236048**

Thank you for your letter of 01 Feb 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter [Cover Letter Addressing Provisional Opinion]		01 February 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		24 July 2017
GP/consultant information sheets or letters [Clinician information letter]	2	24 January 2018
Interview schedules or topic guides for participants [Interview schedule]	1	06 November 2017
IRAS Application Form [IRAS_Form_30012018]		30 January 2018
Letter from funder [MRC Letter]		18 April 2016
Letter from sponsor [Sponsor letter]		
Participant consent form [Consent form]	1	21 September 2017
Participant consent form [Carer consent form]	1	21 September 2017
Participant information sheet (PIS) [PIS Interview]	2	24 January 2018
Participant information sheet (PIS) [Focus group PIS]	2	24 January 2018
Participant information sheet (PIS) [PIS Carer]	2	24 January 2018
Referee's report or other scientific critique report [Project approval form]		06 November 2017
Research protocol or project proposal	2	24 January 2018
Summary CV for Chief Investigator (CI) [Summary CV]		08 November 2017
Summary CV for student [Student CV]		08 November 2017
Summary CV for supervisor (student research)		06 November 2017
Summary CV for supervisor (student research)		08 November 2017
Summary CV for supervisor (student research) [Supervisor CV]		08 November 2017
Validated questionnaire [EDE-Q]		01 January 2008
Validated questionnaire [Body Shape Questionnaire]		01 January 1986
Validated questionnaire [Compulsive Exercise Test]		
Validated questionnaire [AQ-28]		
Validated questionnaire [SWEAA]		
Validated questionnaire [HADS]		
Validated questionnaire [Friendship Questionnaire]		
Validated questionnaire [The Unidimensional Relationship Closeness Scale]		
Validated questionnaire [Columbia Suicide Rating Scale]		01 February 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/LO/0050	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp Dr John Keen
Chair
Email:nrescommittee.london-cityandeast@nhs.net

NHS
Health Research Authority
North East - Newcastle & North Tyneside 2 Research Ethics Committee

NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Tel: 0207 104 8082

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

03 June 2018

Dr Kate Tchanturia
Section of Eating Disorders
King's College London
103 Denmark Hill, London
SE5 8AF

Dear Dr Tchanturia

Study title:	**Investigating Sensory Processing in Autism Spectrum Disorder and Anorexia Nervosa**
REC reference:	**18/NE/0193**
Protocol number:	**n/a**
IRAS project ID:	**244248**

The Proportionate Review Sub-committee of the North East - Newcastle & North Tyneside 2 Research Ethics Committee reviewed the above application on 01 June 2018.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point,

wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Include the wording to the Participant Information Sheet: "You will be paid £20 for taking part in the study, for which this payment MAY have to be declared for tax purposes or it could affect any state payments you may be receiving."

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

Summary of discussion at the meeting

Social or scientific value; scientific design and conduct of the study

Members requested that a more detailed explanation of what would happen and what the tests would entail was needed as not being able to eat food was not sufficient.

The applicant replied that they had expanded the explanation to "This will include experiments testing your ability to smell, your ability to taste, your responses to textures, and your ability to reflect on your internal sensations. Although we are looking at food-related sensory processing in the research, you will not be asked to consume food during the experiments. Instead, you will be presented with different smells and asked to identify the smell. For taste, a small filter paper disc imbued with a particular taste will be placed on your tongue and you will be asked to identify the taste. This will then be removed and you will be able to wash your mouth out with water. For texture, you will be blindfolded, given a non-food material, and asked to identify the material. For internal sensations you will be asked to count your heartbeats."

Members requested a more accurate detail of the time they would need to give up needed to be indicated.

The applicant replied that they had added the sentence "In total the study will take between an hour and a half and two hours" and submitted the document for review.

The Sub Committee was satisfied with the responses given to the issues raised.

Recruitment arrangements and access to health information, and fair participant selection

Members requested the scientific justification for the cut off of 55 years

The applicant replied that this current study was examining taste, smell sensitivity, and research suggested that sensitivity declined with age. Previous research suggested that this decline began around age 60 (e.g. https://academic.oup.com/chemse/article/28/5/397/349656), age 55 was chosen as a cut off as this was clearly below the point of potential age-related deterioration beginning.

The Sub Committee was satisfied with the response given to the issue raised.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

Members stated that personal data only needed to be kept for long enough to inform patients of the results and research data could be kept for 7 years.

The applicant replied that this had been made clearer- "This research data will be kept securely for a period of 7 years in line with King's College London policy on data handling and storage. Your personal data will only be kept as long as required to notify you of the results (if requested) and will then be destroyed." The document was submitted for review.

The Sub Committee was satisfied with the response given to the issue raised.

Informed consent process and the adequacy and completeness of participant information

Members stated that the Participant Information Sheet (PIS) was to include that the interviews would be video/audio recorded.

The applicant replied that the following sentence was added "You will then be asked to complete some questionnaires and an interview, which will be audio and video recorded."

Members asked that when indicating the benefits they were to make it clear that participants may not have any benefit but the hope was future patients would.

The applicant replied that the following sentence was added "You will be paid £20 for taking part in the study. It is unlikely that you will receive any other specific benefits from participating in this study, however, we hope that this research will benefit future individuals receiving eating disorder treatment."

Members stated that the PIS header should read "Will it be possible to identify me from my results?"

The applicant replied that this was amended.

Members recommended that the PIS / ICF should refer to GDPR rather than data protection act.

The applicant replied that the following sentence was amended to "Your participation in the study will be confidential and will be handled in accordance with the terms of GDPR legislation."

Members stated in the PIS "If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. Your participation in this study will not be affected should you choose not to be re-contacted" needed to be Optional and also on the Consent Form, along with Items 8 and 10 as optional.

The applicant replied that the documentation was amended and options added on the consent form "If you agree to take part in this study you will be asked whether you are happy to be contacted about participation in future studies, however, this is completely optional. Your participation in this study will not be affected should you choose not to be re-contacted."

Members stated that the £20 payment could affect participants' benefits; therefore this needed to be included in PIS

The applicant replied that they had added the sentence "You will be paid £20 for taking part in the study. It is unlikely that you will receive any other specific benefits from participating in this study, however, we hope that this research will benefit future individuals receiving eating disorder treatment" to Participant Information Sheet.

The Sub Committee was not satisfied with the above change and requested that the wording be changed to the following "You will be paid £20 for taking part in the study, for which this payment MAY have to be declared for tax purposes or it could affect any state payments you may be receiving."

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [BEAT Advert]	1	13 November 2017
Copies of advertisement materials for research participants [Email circular]	1	12 March 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [KCL Insurance]		24 July 2017
IRAS Application Form [IRAS_Form_20052018]		20 May 2018
Letter from funder [Funding letter]	1	18 April 2016
Letter from sponsor [Sponsorship letter]		16 April 2018
Non-validated questionnaire [Demographics]	1	14 April 2018
Participant consent form [Patient]	Version 2	31 May 2018
Participant consent form [Healthy Control]	Version 2	31 May 2018
Participant information sheet (PIS) [Patient]	Version 2	31 May 2018
Participant information sheet (PIS) [Healthy Control]	Version 2	31 May 2018

Referee's report or other scientific critique report [Project approval]		30 August 2017
Research protocol or project proposal [Protocol]	1	20 February 2018
Summary CV for Chief Investigator (CI) [CI_CV]		21 October 2014
Summary CV for student [Student CV]	1	02 March 2018
Summary CV for supervisor (student research) [Catherine Stewart CV]	1	02 March 2018
Summary CV for supervisor (student research) [Kate Tchanturia CV]	1	02 March 2018
Validated questionnaire [Autism Quotient]		
Validated questionnaire [Body Perception Questionnaire]		
Validated questionnaire [Eating Disorder Examination Questionnaire]		
Validated questionnaire [Hospital Anxiety and Depression Scale]		
Validated questionnaire [Sensory Perception Quotient]		
Validated questionnaire [Work and Social Adjustment Scale]		
Validated questionnaire [Toronto Alexithymia Scale]		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

18/NE/0193	**Please quote this number on all correspondence**

Yours sincerely

pp

Ms Emma Thompson
Chair

Email: nrescommittee.northeast-newcastleandnorthtyneside2@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
	"After ethical review – guidance for researchers"
Copy to:	*Prof Reza Razavi* *Ms Jennifer Liebscher, South London and Maudsley NHS Foundation Trust*

Appendix B: Participant Information Sheets

Qualitative information sheets are presented first, followed by sensory information.

Version 1, 21/09/2017 IRAS ID 236048

INFORMATION SHEET FOR PARTICIPANTS (INTERVIEW)

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: Beyond the stereotypes: characterising the unique features of under-researched eating disorder populations, and implications for treatment.

Invitation and brief summary:
We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. We would really appreciate your involvement as this study will help to improve our understanding of eating disorders and may help us to develop future treatments.

What is the purpose of the study?
The purpose of this study is to look at how far current treatment approaches meet the needs of certain people with eating disorders, and whether these groups would benefit from treatment adaptations.

What is the background of the study?
Existing research suggests that men with eating disorders, and individuals with comorbid anorexia and autism, may have different treatment needs. Further research is needed to explore these needs and how these might be translated into changes to treatment.

What would taking part involve?
If you decide you would like to take part, a researcher will contact you to discuss the study. This will take about ten minutes and you will be asked a number of questions to assess whether you are able to take part in the study. If you are eligible to take part in the study, you will be invited for an interview. This will either take place at your place of treatment, or at the IOPPN, and is likely to take no more than 45 minutes. You can also choose to do the interview over Skype from your home. The session will be audio-recorded. You will also be asked to separately complete some online questionnaires: participation in these is not compulsory, and a decision not to complete the questionnaires will not prevent you from participating in the interview.

If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. Your participation in this study will not be affected should you choose not to be re-contacted.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation and have your data withdrawn at any time without giving a reason.

What happens next?
One of the researchers will contact you to answer any questions you may have and ask whether you would like to take part in the study.

What are the benefits of taking part?
We hope that this research will benefit future individuals receiving eating disorder treatment.

What are the possible disadvantages or risks of taking part?
There are no major risks associated with taking part in this study. The study will take up some of your time. If you find any of the questions upsetting, please talk to your care team. You can withdraw from the study at any point.

Will it possible to identify me from my results?
Your participation in the study will be confidential. From the beginning of your involvement, you will be given an identification number and this will be used to match your completed measures rather than your name. Your data will be kept on a password protected computer and in locked storage. This data will be kept securely for a period of 4 years, in accordance with the Data Protection Act. Your name will not appear anywhere in any publication or in any description of the findings. Only the researchers and supervisors will be allowed to see your files.

Who is organising / funding the research?
The research is being organised by the Institute of Psychiatry. The researcher is being supported by a Medical Research Council PhD studentship.

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London - City & East Research Ethics Committee.

What should I do if there is a problem?
Complaints should be addressed to Dr Gill Dale for research in SLaM. Director of Research Quality; Head, Joint R&D Office of South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, Psychology & Neuroscience (IoPPN), P005, Institute of Psychiatry, Psychology & Neuroscience (IoPPN), King's College London, De Crespigny Park, London SE5 8AF.

What should I do if I want more information?
For more information on any aspect of the study please contact one of the researchers using the contact details below.

Emma Kinnaird
Emma.kinnaird@kcl.ac.uk

Supervisor: Dr Kate Tchanturia
Kate.tchanturia@kcl.ac.uk

Institute of Psychiatry
Section of Eating Disorders
103 Denmark Hill
London SE5 8AF
0207 8480160

Version 2, 24/01/2018 IRAS ID 236048

INFORMATION SHEET FOR CARERS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: Beyond the stereotypes: characterising the unique features of under-researched eating disorder populations, and implications for treatment.

Invitation and brief summary:
We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. We would really appreciate your involvement as this study will help to improve our understanding of eating disorders and may help us to develop future treatments.

What is the purpose of the study?
The purpose of this study is to look at how far current treatment approaches meet the needs of certain people with eating disorders, and whether these groups would benefit from treatment adaptations.

What is the background of the study?
Existing research suggests that men with eating disorders, and individuals with comorbid anorexia and autism, may have different treatment needs. Further research is needed to explore these needs and how these might be translated into changes to treatment.

What would taking part involve?
If you decide you would like to take part, a researcher will contact you to discuss the study. This will take about ten minutes and you will be asked a number of questions to assess whether you are able to take part in the study. If you are eligible to take part in the study, you will be invited for an interview. This will either take place at your place of treatment, or at the Institute of Psychiatry, Psychology and Neuroscience at Denmark Hill, and is likely to take no more than 45 minutes. You will be compensated for your travel costs. You can also choose to do the interview over Skype from your home. The session will be audio-recorded.

If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. Your participation in this study will not be affected should you choose not to be re-contacted.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation and have your data withdrawn at any time without giving a reason.

What will participation involve?

What happens next?

One of the researchers will contact you to answer any questions you may have and ask whether you would like to take part in the study.

What are the benefits of taking part?
We hope that this research will benefit future individuals receiving eating disorder treatment.

What are the possible disadvantages or risks of taking part?
There are no major risks associated with taking part in this study. The study will take up some of your time. You can withdraw from the study at any point.

Will it possible to identify me from my results?
Your participation in the study will be confidential. From the beginning of your involvement, you will be given an identification number and this will be used to match your completed measures rather than your name. Your data will be kept on a password protected computer and in locked storage. This data will be kept securely for a period of 4 years. Your name will not appear anywhere in any publication or in any description of the findings. Only the researchers and supervisors will be allowed to see your files.

Who is organising / funding the research?
The research is being organised by the Institute of Psychiatry. The researcher is being supported by a Medical Research Council PhD studentship.

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London - City & East Research Ethics Committee.

What should I do if there is a problem?
Complaints should be addressed to Dr Gill Dale for research in SLaM. Director of Research Quality; Head, Joint R&D Office of South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, Psychology & Neuroscience (IoPPN), P005, Institute of Psychiatry, Psychology & Neuroscience (IoPPN), King's College London, De Crespigny Park, London SE5 8AF.

What should I do if I want more information?
For more information on any aspect of the study please contact one of the researchers using the contact details below.

Emma Kinnaird
Emma.kinnaird@kcl.ac.uk

Supervisor: Dr Kate Tchanturia
Kate.tchanturia@kcl.ac.uk

Institute of Psychiatry
Section of Eating Disorders
103 Denmark Hill
London SE5 8AF
0207 8480160

INFORMATION SHEET FOR HEALTHY CONTROLS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: Investigating Sensory Processing in Autism Spectrum Disorder and Anorexia Nervosa

Invitation and brief summary:
We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. We would really appreciate your involvement as this study will help to improve our understanding of eating disorders and may help us to develop future treatments.

What is the purpose of the study?
The purpose of this study is to look at whether individuals with anorexia nervosa (AN) only, experience difficulties with sensory processing, and whether this is affected by the presence of autistic traits.

What is the background of the study?
We know that both people with autism and people with AN say that they avoid or dislike certain sensations, such as specific textures or tastes. The purpose of this research is to explore this area in more detail. We will look at both sensory processing around food (for example, smell or taste), and internal sensory processing (for example, the ability to tell if you feel hungry). We hope that better understanding of this area will give us an insight into the difficulties experienced both by people with AN only, and by those with comorbid autism.

What would taking part involve?
If you decide to take part, a member of the research team will contact you to discuss any questions you may have about the study and arrange an appointment either at your place of treatment, or at the Institute of Psychiatry, Psychology and Neuroscience (IoPPN). At the appointment, you will be asked to sign a consent form. You will then be asked to complete some questionnaires and an interview, which will be audio and video recorded.

You will then complete a series of tasks designed to assess your sensory processing. This will include experiments testing your ability to smell, your ability to taste, your responses to textures, and your ability to reflect on your internal sensations. Although we are looking at food-related sensory processing in the research, you will not be asked to consume food

during the experiments. Instead, you will be presented with different smells and asked to identify the smell. For taste, a small filter paper disc imbued with a particular taste will be placed on your tongue and you will be asked to identify the taste. This will then be removed and you will be able to wash your mouth out with water. For texture, you will be blindfolded, given a non-food material, and asked to identify the material. For internal sensations you will be asked to count your heartbeats. In total the study will take between an hour and a half and two hours.

If you agree to take part in this study you will be asked whether you are happy to be contacted about participation in future studies, however, this is completely optional. Your participation in this study will not be affected should you choose not to be re-contacted.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation and have your data withdrawn at any time without giving a reason.

What happens next?
One of the researchers will contact you to answer any questions you may have and ask whether you would like to take part in the study.

What are the benefits of taking part?
You will be paid £20 for taking part in the study, for which this payment MAY have to be declared for tax purposes or it could affect any state payments you may be receiving. It is unlikely that you will receive any other specific benefits from participating in this study, however, we hope that this research will benefit future individuals receiving eating disorder treatment.

What are the possible disadvantages or risks of taking part?
There are no major risks associated with taking part in this study. The study will take up some of your time. If you find any of the questions upsetting, please talk to your care team. You can withdraw from the study at any point. There is a possibility that some of the measures used may suggest that you have previously undiagnosed autism traits: with your permission, your clinical care team will be informed of this possibility and they will decide what future action to take.

Please note that you will be asked to provide your current weight.

Will it be possible to identify me from my results?
Your participation in the study will be confidential and will be handled in accordance with the terms of GDPR legislation. From the beginning of your involvement, you will be given an identification number and this will be used to match your completed measures rather than your name. Your data will be kept on a password protected computer and in locked storage. Your name will not appear anywhere in any publication or in any description of the findings. Only the researchers and supervisors will be allowed to see your files.

King's College London (KCL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. This research data will be kept securely for a period of 7 years in line with King's College London policy on data handling and storage. Your

personal data will only be kept as long as required to notify you of the results (if requested) and will then be destroyed.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Emma Kinnaird (details below).

Who is organising / funding the research?
The research is being organised by the Institute of Psychiatry. The researcher is being supported by a Medical Research Council PhD studentship.

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North East Newcastle & North Tyneside 2 Research Ethics Committee.

What should I do if there is a problem?
For complaints to South London and Maudsley NHS Foundation Trust (SLaM), the SLaM complaints mechanism should be used. Complaints to the IoPPN should be addressed to Dr Gill Dale. Director of Research Quality; Head, Joint R&D Office of South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, Psychology & Neuroscience (IoPPN), P005, Institute of Psychiatry, Psychology & Neuroscience (IoPPN), King's College London, De Crespigny Park, London SE5 8AF.

What should I do if I want more information?
For more information on any aspect of the study please contact one of the researchers using the contact details below.

Emma Kinnaird
Emma.kinnaird@kcl.ac.uk

Supervisor: Dr Kate Tchanturia
Kate.tchanturia@kcl.ac.uk

Institute of Psychiatry
Section of Eating Disorders
103 Denmark Hill
London SE5 8AF
0207 8480160

NHS
South London and Maudsley
NHS Foundation Trust

KING'S College LONDON

INFORMATION SHEET FOR PATIENTS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: Investigating Sensory Processing in Autism Spectrum Disorder and Anorexia Nervosa

Invitation and brief summary:
We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. We would really appreciate your involvement as this study will help to improve our understanding of eating disorders and may help us to develop future treatments.

What is the purpose of the study?
The purpose of this study is to look at whether individuals with anorexia nervosa (AN) only, experience difficulties with sensory processing, and whether this is affected by the presence of autistic traits.

What is the background of the study?
We know that both people with autism and people with AN say that they avoid or dislike certain sensations, such as specific textures or tastes. The purpose of this research is to explore this area in more detail. We will look at both sensory processing around food (for example, smell or taste), and internal sensory processing (for example, the ability to tell if you feel hungry). We hope that better understanding of this area will give us an insight into the difficulties experienced both by people with AN only, and by those with comorbid autism.

What would taking part involve?
If you decide to take part, a member of the research team will contact you to discuss any questions you may have about the study and arrange an appointment either at your place of treatment, or at the Institute of Psychiatry, Psychology and Neuroscience (IoPPN). At the appointment, you will be asked to sign a consent form. You will then be asked to complete some questionnaires and an interview, which will be audio and video recorded.

You will then complete a series of tasks designed to assess your sensory processing. This will include experiments testing your ability to smell, your ability to taste, your responses to textures, and your ability to reflect on your internal sensations. Although we are looking at food-related sensory processing in the research, you will not be asked to consume food

during the experiments. Instead, you will be presented with different smells and asked to identify the smell. For taste, a small filter paper disc imbued with a particular taste will be placed on your tongue and you will be asked to identify the taste. This will then be removed and you will be able to wash your mouth out with water. For texture, you will be blindfolded, given a non-food material, and asked to identify the material. For internal sensations you will be asked to count your heartbeats. In total the study will take between an hour and a half and two hours.

If you agree to take part in this study you will be asked whether you are happy to be contacted about participation in future studies, however, this is completely optional. Your participation in this study will not be affected should you choose not to be re-contacted.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation and have your data withdrawn at any time without giving a reason.

What happens next?
One of the researchers will contact you to answer any questions you may have and ask whether you would like to take part in the study.

What are the benefits of taking part?
You will be paid £20 for taking part in the study, for which this payment MAY have to be declared for tax purposes or it could affect any state payments you may be receiving. It is unlikely that you will receive any other specific benefits from participating in this study, however, we hope that this research will benefit future individuals receiving eating disorder treatment.

What are the possible disadvantages or risks of taking part?
There are no major risks associated with taking part in this study. The study will take up some of your time. If you find any of the questions upsetting, please talk to your care team. You can withdraw from the study at any point. There is a possibility that some of the measures used may suggest that you have previously undiagnosed autism traits: with your permission, your clinical care team will be informed of this possibility and they will decide what future action to take.

Please note that you will be asked to provide your current weight.

Will it be possible to identify me from my results?
Your participation in the study will be confidential and will be handled in accordance with the terms of GDPR legislation. From the beginning of your involvement, you will be given an identification number and this will be used to match your completed measures rather than your name. Your data will be kept on a password protected computer and in locked storage. Your name will not appear anywhere in any publication or in any description of the findings. Only the researchers and supervisors will be allowed to see your files.

King's College London (KCL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. This research data will be kept securely for a period of 7 years in line with King's College London policy on data handling and storage. Your

personal data will only be kept as long as required to notify you of the results (if requested) and will then be destroyed.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Emma Kinnaird (details below).

Who is organising / funding the research?
The research is being organised by the Institute of Psychiatry. The researcher is being supported by a Medical Research Council PhD studentship.

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North East Newcastle & North Tyneside 2 Research Ethics Committee.

What should I do if there is a problem?
For complaints to South London and Maudsley NHS Foundation Trust (SLaM), the SLaM complaints mechanism should be used. Complaints to the IoPPN should be addressed to Dr Gill Dale. Director of Research Quality; Head, Joint R&D Office of South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, Psychology & Neuroscience (IoPPN), P005, Institute of Psychiatry, Psychology & Neuroscience (IoPPN), King's College London, De Crespigny Park, London SE5 8AF.

What should I do if I want more information?
For more information on any aspect of the study please contact one of the researchers using the contact details below.

Emma Kinnaird
Emma.kinnaird@kcl.ac.uk

Supervisor: Dr Kate Tchanturia
Kate.tchanturia@kcl.ac.uk

Institute of Psychiatry
Section of Eating Disorders
103 Denmark Hill
London SE5 8AF
0207 8480160

Appendix C: Consent Forms

Qualitative consent forms are presented first, followed by sensory forms.

Version 1, 21/09/2017

IRAS ID: **236048**

CONSENT FORM

Beyond the stereotypes: characterising the unique features of under-researched eating disorder populations, and implications for treatment.

Name of Researcher: Emma Kinnaird

Please initial box

1. I confirm that I have read the information sheet dated 24/01/2018 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
4. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Version 1, 21/09/2017

IRAS ID: **236048**

CONSENT FORM: CARER

Beyond the stereotypes: characterising the unique features of under-researched eating disorder populations, and implications for treatment.

Name of Researcher: Emma Kinnaird

Please initial box

1. I confirm that I have read the information sheet dated 24/01/2018 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
4. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

IRAS ID 244248
Version 2, 31/05/2018
Participant ID Number:

CONSENT FORM (HEALTHY CONTROL)

Investigating Sensory Processing in Autism Spectrum Disorder and Anorexia Nervosa

Please initial each box to indicate that you consent to each part of the study. If you do not initial, it will be assumed that you do not consent to that part of the study.

	Please initial
1. I confirm that I have read and understood the information sheet dated 02/03/2018, version 1 for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.	☐
2. I understand that participation is voluntary and that I am free to withdraw at any time without giving a reason but that previously collected data may still be used for the purposes of this research	☐
3. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 2018.	☐
4. I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes	☐
5. I understand that my confidentiality and anonymity will be maintained at all times and that it will not be possible to identify me in any publications.	☐
6. I consent to my clinical interview being video/audio recorded	☐
7. I agree that my direct care team may be informed of any potentially new diagnosis that is identified during the course of this research	☐
8. OPTIONAL: I understand that my data may be used in the publication of research reports and I would like to receive a copy of the results of the research	☐

9. **OPTIONAL: I agree to be contacted in the future by King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature** ☐

10. **OPTIONAL: I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report).** ☐

Contact details (optional) - Address

_____

_____

Telephone _____ e-mail _____

Consent

I agree to take part in this study ☐

SIGNED (Participant) **DATE**

....

I confirm that the project has been explained to the participant:

SIGNED (Researcher) **DATE**

....

When completed, 1 for patient, 1 for researcher site file, 1 (original) to be kept with medical notes

IRAS ID 244248
Version 2, 31/05/2018
Participant ID Number:

CONSENT FORM (PATIENT)

Investigating Sensory Processing in Autism Spectrum Disorder and Anorexia Nervosa

Please initial each box to indicate that you consent to each part of the study. If you do not initial, it will be assumed that you do not consent to that part of the study.

	Please initial
1. I confirm that I have read and understood the information sheet dated 02/03/2018, version 1 for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.	☐
2. I understand that participation is voluntary and that I am free to withdraw at any time without giving a reason but that previously collected data may still be used for the purposes of this research	☐
3. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 2018.	☐
4. I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes	☐
5. I understand that my confidentiality and anonymity will be maintained at all times and that it will not be possible to identify me in any publications.	☐
6. I consent to my clinical interview being video/audio recorded	☐
7. I agree that my direct care team may be informed of any potentially new diagnosis that is identified during the course of this research	☐
8. OPTIONAL: I understand that my data may be used in the publication of research reports and I would like to receive a copy of the results of the research	☐

9. **OPTIONAL: I agree to be contacted in the future by King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature** ☐

10. **OPTIONAL: I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report).** ☐

Contact details (optional) - Address

_____

_____

Telephone _____ e-mail _____

Consent

I agree to take part in this study ☐

SIGNED (Participant) **DATE**

....

I confirm that the project has been explained to the participant:

SIGNED (Researcher) **DATE**

....

When completed, 1 for patient, 1 for researcher site file, 1 (original) to be kept with medical notes

Appendix D: Interview Schedules

Interview schedule for clinicians

Question
Do you work differently with men and women with EDs?
When treating men, do you look for any male-specific issues during treatment?
What do you think our strengths are in our service treating men with EDs?
What could be improved?
What do you do if your patient with an eating disorder has an autism spectrum disorder diagnosis or traits?

Interview schedule for men with EDs

Question	Follow-up questions/ prompts (optional)
What is your formal diagnosis?	How long have you been diagnosed?
Is this your first time in treatment?	What treatment have you had before? Was it in this service?
What did you expect treatment to involve before you started?	Did you have any expectations? What did you think the therapeutic process would be like? Were these based on your prior experiences? Do you think these perceptions affected how you first engaged with treatment?
What do you feel has been good about your treatment?	Is there any single coping strategy, technique, or advice that's been particularly helpful to you?
Have there been any problems or issues you've had with treatments offered?	Were these problems resolved? Did you tell anyone about these problems? How did this affect your engagement with treatment? Why do you think these problems occurred?
How do you think treatment for men with EDs could be improved?	Is there anything not currently offered that you think could be particularly helpful to you? Is there anything currently offered that you'd like to have more of?
Do you think there's a difference between the kind of treatments required by men and women?	Why not? Why do you think these differences exist?
Do you feel like clinicians have adapted your treatment to fit any male-specific issues you may have experienced?	How have they done this? How well have they done this?
How well do you think the service provides treatments for men with EDs?	
What would you like to see improved?	
We interviewed clinicians and they made some suggestions for male-specific treatment that I'd like to get your feedback on: • Male only therapy groups • Male therapists for male patients	Why do you think these would work better/ wouldn't work?

Interview schedule for autistic people with AN

Question	Follow-up questions/ prompts (optional)
What is your formal diagnosis?	How long have you been diagnosed with AN? When were you diagnosed with ASD? Have you been diagnosed with anything else- e.g. anxiety, depression?
If inpatient Is this your first time in treatment?	What treatment have you had before? **If inpatient** Was it in this service?
If online recruit Do you consider yourself recovered from AN?	
If online recruit Could you talk me through the treatments you've had for AN?	
What did you expect treatment to involve before you started?	Did you have any expectations? What did you think the therapeutic process would be like? Were these based on your prior experiences? Do you think these perceptions affected how you first engaged with treatment?
Do you feel like you were given enough information?	
What do you feel has been good about your treatment?	Is there any single coping strategy, technique, or advice that's been particularly helpful to you?
Have there been any problems or issues you've had with treatments offered?	Were these problems resolved? Did you tell anyone about these problems? How did this affect your engagement with treatment? Why do you think these problems occurred?
Do you have any sensory difficulties around food?	E.g. Texture, temperature.
How do you find food shopping and cooking?	
How did you find the treatment environment?	**If individual has received inpatient/day patient treatment** How did you find the dining room environment?
If individual has confirmed that they have an ASD diagnosis How do you think treatment for people with AN/ASD could be improved?	Is there anything not currently offered that you think could be particularly helpful to you? Is there anything currently offered that you'd like to have more of?
If individual has confirmed that they have an ASD diagnosis How well do you think that existing understandings of AN apply to you as an autistic person?	Do you think there is a relationship between your autism and your anorexia? Do you have any symptoms which you think are related more to your autism than your anorexia?
If individual has confirmed that they have an ASD diagnosis Do you think there's a difference between the kind of treatments required by people with AN/ASD, and people with AN only?	Why not? *or* Why do you think these differences exist?
If individual has confirmed that they have an ASD diagnosis Do you feel like clinicians have adapted your treatment for your ASD?	How have they done this? How well did they do this?
How would you define recovery?	How do you view the relationship between recovering from AN to your ASD?

Interview schedule for carers of autistic people with AN

Question	Follow-up questions/ prompts (optional)
Does your loved one have a formal diagnosis?	How long have you they been diagnosed with AN? When were they diagnosed with ASD?
Is this their first time in treatment?	What treatment have you they had before? Specify: out/in patient, therapy, medication etc.
Did you/loved one experience difficulty accessing services because of co-occurring ASD?	
Do you feel like the ASD was taken into account in previous treatments?	Where treatments modified? If so – what were the modifications?
What is your experience (carers) of the diagnostic process for ASD	
Do you think someone with AN/ASD has additional support needs?	Were they being met? What could be done differently to meet these needs?
What do you feel has been good about their current/previous treatment?	
Have there been any problems or issues you've had with treatments offered?	Were these problems resolved? Did you tell anyone about these problems? How did this affect your engagement with treatment? As a carer Why do you think these problems occurred?
How do you think treatment for people with AN/ASD could be improved?	Is there anything not currently offered that you think could be particularly helpful for you as a carer? Is there anything not currently offered that you think could be particularly helpful to them as a patient? Is there anything currently offered that you'd like to have more of?
Do you think there's a difference between the kind of treatments required by people with AN/ASD, and people with AN only?	Why not? Why do you think these differences exist?
Do you feel like clinicians have adapted the treatment for your ASD?	How have they done this? How well did they do this?
How would you define recovery?	How do you view the relationship between recovering from AN and/or ASD?
Do you feel involved in the treatment process?	What works? What can be changed? Did/do you feel listened to?
Any further thoughts?	

Interview schedule for autistic people on eating problems.

Question	Follow-up questions/ prompts (optional)
How old are you?	
What kind of autism diagnosis do you have?	How long have you been diagnosed with ASD? Any eating disorder diagnosis? Any medical problems which affect your eating? E.g. Allergies?
What is your current weight and height?	
Do you have, or have you ever had, an eating disorder?	
Are you on any special diet?	
Do you think that your autism affects your eating?	For example, food selectivity, restricted eating. Did you have difficulty eating as a child? Have these behaviours changed over time?
IF EATING DISORDER how well do you feel that existing models of your eating disorder apply to you and your experiences?	
Do you have any food sensitivities?	E.g. Taste, texture, temperature Did you have them as a child? Have they changed over time? Do your food sensitivities affect the way you eat?
How about the environment surrounding eating?	E.g. In front of people, in a loud restaurant
Do you have any routines or special interests surrounding food?	
Do you find that you still manage to get all of your nutritional needs from the food that you eat?	Have you ever been underweight or overweight?
How does autism and eating affect your life?	
How do you cope with your food difficulties?	
How do other people react to your eating habits?	Is there anything other people can do to support you? Very visual- if someone moves food, forgets. Problems living in shared house.
What would you like neurotypical people to know about eating and autism?	
What would you like medical professionals to know about eating and autism?	

Appendix E: Questionnaire Measures

Autism Quotient (AQ; Baron-Cohen, et al., 2001). AQ-10 items are highlighted in bold (Allison, et al., 2012).

Below are a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer.

1. I prefer to do things with others rather than on my own.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I prefer to do things the same way over and over again.	definitely agree	slightly agree	slightly disagree	definitely disagree
3. If I try to imagine something, I find it very easy to create a picture in my mind.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. I frequently get so strongly absorbed in one thing that I lose sight of other things.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. **I often notice small sounds when others do not.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
6. I usually notice car number plates or similar strings of information.	definitely agree	slightly agree	slightly disagree	definitely disagree
7. Other people frequently tell me that what I've said is impolite, even though I think it is polite.	definitely agree	slightly agree	slightly disagree	definitely disagree
8. When I'm reading a story, I can easily imagine what the characters might look like.	definitely agree	slightly agree	slightly disagree	definitely disagree
9. I am fascinated by dates.	definitely agree	slightly agree	slightly disagree	definitely disagree
10. In a social group, I can easily keep track of several different people's conversations.	definitely agree	slightly agree	slightly disagree	definitely disagree
11. I find social situations easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
12. I tend to notice details that others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
13. I would rather go to a library than a party.	definitely agree	slightly agree	slightly disagree	definitely disagree
14. I find making up stories easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
15. I find myself drawn more strongly to people than to things.	definitely agree	slightly agree	slightly disagree	definitely disagree

16. I tend to have very strong interests which I get upset about if I can't pursue.	definitely agree	slightly agree	slightly disagree	definitely disagree
17. I enjoy social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
18. When I talk, it isn't always easy for others to get a word in edgeways.	definitely agree	slightly agree	slightly disagree	definitely disagree
19. I am fascinated by numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
20. **When I'm reading a story, I find it difficult to work out the characters' intentions.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
21. I don't particularly enjoy reading fiction.	definitely agree	slightly agree	slightly disagree	definitely disagree
22. I find it hard to make new friends.	definitely agree	slightly agree	slightly disagree	definitely disagree
23. I notice patterns in things all the time.	definitely agree	slightly agree	slightly disagree	definitely disagree
24. I would rather go to the theatre than a museum.	definitely agree	slightly agree	slightly disagree	definitely disagree
25. It does not upset me if my daily routine is disturbed.	definitely agree	slightly agree	slightly disagree	definitely disagree
26. I frequently find that I don't know how to keep a conversation going.	definitely agree	slightly agree	slightly disagree	definitely disagree
27. **I find it easy to "read between the lines" when someone is talking to me.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
28. **I usually concentrate more on the whole picture, rather than the small details.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
29. I am not very good at remembering phone numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
30. I don't usually notice small changes in a situation, or a person's appearance.	definitely agree	slightly agree	slightly disagree	definitely disagree
31. **I know how to tell if someone listening to me is getting bored.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
32. **I find it easy to do more than one thing at once.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**

33. When I talk on the phone, I'm not sure when it's my turn to speak.	definitely agree	slightly agree	slightly disagree	definitely disagree
34. I enjoy doing things spontaneously.	definitely agree	slightly agree	slightly disagree	definitely disagree
35. I am often the last to understand the point of a joke.	definitely agree	slightly agree	slightly disagree	definitely disagree
36. **I find it easy to work out what someone is thinking or feeling just by looking at their face.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
37. **If there is an interruption, I can switch back to what I was doing very quickly.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
38. I am good at social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
39. People often tell me that I keep going on and on about the same thing.	definitely agree	slightly agree	slightly disagree	definitely disagree
40. When I was young, I used to enjoy playing games involving pretending with other children.	definitely agree	slightly agree	slightly disagree	definitely disagree
41. **I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
42. I find it difficult to imagine what it would be like to be someone else.	definitely agree	slightly agree	slightly disagree	definitely disagree
43. I like to plan any activities I participate in carefully.	definitely agree	slightly agree	slightly disagree	definitely disagree
44. I enjoy social occasions.	definitely agree	slightly agree	slightly disagree	definitely disagree
45. **I find it difficult to work out people's intentions.**	**definitely agree**	**slightly agree**	**slightly disagree**	**definitely disagree**
46. New situations make me anxious.	definitely agree	slightly agree	slightly disagree	definitely disagree
47. I enjoy meeting new people.	definitely agree	slightly agree	slightly disagree	definitely disagree
48. I am a good diplomat.	definitely agree	slightly agree	slightly disagree	definitely disagree
49. I am not very good at remembering people's date of birth.	definitely agree	slightly agree	slightly disagree	definitely disagree

50. I find it very easy to play games with children that involve pretending.	definitely agree	slightly agree	slightly disagree	definitely disagree

Body Perception Questionnaire (BPQ; Porges, 1993)

Imagine how aware you are of your body processes. Select the answer that most accurately describes you. Rate your awareness on each of the characteristics described below using the following 5-point scale: a) Never b) Occasionally c) Sometimes d) Usually e) Always.

During most situations I am aware of:

Swallowing frequently	Never	Occasionally	Sometimes	Usually	Always
A ringing in my ears	Never	Occasionally	Sometimes	Usually	Always
An urge to cough to clear my throat	Never	Occasionally	Sometimes	Usually	Always
My body swaying when I am standing	Never	Occasionally	Sometimes	Usually	Always
My mouth being dry	Never	Occasionally	Sometimes	Usually	Always
How fast I am breathing	Never	Occasionally	Sometimes	Usually	Always
Watering or tearing of my eyes	Never	Occasionally	Sometimes	Usually	Always
My skin itching	Never	Occasionally	Sometimes	Usually	Always
Noises associated with my digestion	Never	Occasionally	Sometimes	Usually	Always
Eye fatigue or pain	Never	Occasionally	Sometimes	Usually	Always
Muscle tension in my back and neck	Never	Occasionally	Sometimes	Usually	Always
A swelling of my body or parts of my body	Never	Occasionally	Sometimes	Usually	Always
An urge to urinate	Never	Occasionally	Sometimes	Usually	Always
Tremor in my hands	Never	Occasionally	Sometimes	Usually	Always
An urge to defecate	Never	Occasionally	Sometimes	Usually	Always
Muscle tension in my arms and legs	Never	Occasionally	Sometimes	Usually	Always
Goose bumps	Never	Occasionally	Sometimes	Usually	Always
Facial twitches	Never	Occasionally	Sometimes	Usually	Always
Being exhausted	Never	Occasionally	Sometimes	Usually	Always
Stomach and gut pains	Never	Occasionally	Sometimes	Usually	Always
Rolling or fluttering my eyes	Never	Occasionally	Sometimes	Usually	Always
Stomach distension or bloatedness	Never	Occasionally	Sometimes	Usually	Always
Palms sweating	Never	Occasionally	Sometimes	Usually	Always
Sweat on my forehead	Never	Occasionally	Sometimes	Usually	Always
Clumsiness or bumping into people	Never	Occasionally	Sometimes	Usually	Always
Tremor in my lips	Never	Occasionally	Sometimes	Usually	Always
Sweat in my armpits	Never	Occasionally	Sometimes	Usually	Always
Sensations of prickling, tingling, or numbness in my body	Never	Occasionally	Sometimes	Usually	Always
The temperature of my face (especially my ears)	Never	Occasionally	Sometimes	Usually	Always
Grinding my teeth	Never	Occasionally	Sometimes	Usually	Always
General jitteriness	Never	Occasionally	Sometimes	Usually	Always
Muscle pain	Never	Occasionally	Sometimes	Usually	Always
Joint pain	Never	Occasionally	Sometimes	Usually	Always
Fullness of my bladder	Never	Occasionally	Sometimes	Usually	Always
My eye movements	Never	Occasionally	Sometimes	Usually	Always
Back pain	Never	Occasionally	Sometimes	Usually	Always
My nose itching	Never	Occasionally	Sometimes	Usually	Always

The hair on the back of my neck "standing up"	Never	Occasionally	Sometimes	Usually	Always
Needing to rest	Never	Occasionally	Sometimes	Usually	Always
Difficulty in focusing	Never	Occasionally	Sometimes	Usually	Always
An urge to swallow	Never	Occasionally	Sometimes	Usually	Always
How hard my heart is beating	Never	Occasionally	Sometimes	Usually	Always
Feeling constipated	Never	Occasionally	Sometimes	Usually	Always

Brief Sensory Screener (Chapter 13)

Mark where you think you are on the below scales. Hypersensitivity means you are highly sensitive to sensations and may try and avoid them where possible; hyposensitivity means you have lower sensitivity and may try to seek out these sensations. There are examples below each scale. If you think you are neither hyper/hyposensitive and have no sensory differences, mark yourself in the middle as a 5.

Taste

0	1	2	3	4	5	6	7	8	9	10

(Hyposensitive) (No sensory differences) (Hypersensitive)

If I am hyposensitive, I might add lots of salt to my food to make it taste stronger. If I am hypersensitive, I might prefer to eat bland foods as I find them too strong.

Smell

0	1	2	3	4	5	6	7	8	9	10

(Hyposensitive) (No sensory differences) (Hypersensitive)

If I am hyposensitive, I might not notice strong smells and enjoy smelling essential oils. If I am hypersensitive, I might dislike smelly places like a canteen and find smells overpowering.

Vision

0	1	2	3	4	5	6	7	8	9	10

(Hyposensitive) (No sensory differences) (Hypersensitive)

If I am hyposensitive, I might really like watching bright light displays. If I am hypersensitive, I might prefer to have lights dimmed or turned off.

Sound

0	1	2	3	4	5	6	7	8	9	10

(Hyposensitive) (No sensory differences) (Hypersensitive)

If I am hyposensitive, I might turn my music up loud and dislike silence. If I am hypersensitive, I might dislike loud spaces and put my hands over my ears.

Touch

0	1	2	3	4	5	6	7	8	9	10

(Hyposensitive) (No sensory differences) (Hypersensitive)

If I am hyposensitive, I might enjoy rubbing my hands on soft fabric or a soft toy. If I am hypersensitive, I might dislike and avoid touching certain fabrics.

Texture

0	1	2	3	4	5	6	7	8	9	10

(Hyposensitive) (No sensory differences) (Hypersensitive)

If I am hyposensitive, I might really enjoy the feeling of certain food textures in my mouth (such as liking crunchy food). If I am hypersensitive, I might strongly dislike and avoid eating certain food textures (such as mashed potato).

Demographics Questionnaire

Date of birth: _ _/ _ _ / _ _ Age: __ __

Gender:

o Cis female o Cis male

o Trans female o Trans male

o Non-binary o Prefer not to say

Is English your first language? Yes / No

What is your ethnicity? .....

Are you currently receiving any medication (including the contraceptive pill)? Yes / No

If yes, please give details ……

Have you ever been diagnosed with a neurological condition? Yes / No

If yes, please give details……

Are you left or right handed? …….

Do you currently, or have you ever, smoked? Currently/ Previous/ No

If "Previous", how long ago did you stop?.....

Have you ever been diagnosed with autism? Yes/No

If you have been diagnosed with autism, how old were you when you received this diagnosis? …….

Have you ever been diagnosed with an eating disorder? Yes / No

What eating disorder have you been diagnosed with (please specify subtype if AN)? ……

If you have been diagnosed with an eating disorder, how old were you when you were first diagnosed? ……

What (if any) treatment are you currently receiving and/or have received? ……

……

Have you ever been diagnosed with any other psychiatric illness (please specify)?

……

What is your current weight and height? …….

What is the lowest ever weight you have been (as an adult)? …….

What is the highest ever weight you have been (as an adult)? ……

What is your current employment status?

o Full time o Retired

o Part time o Sick leave

o Unemployed o House wife / husband

o Student o Other ……..……(please specify)

What is the highest level of education you completed?

o No qualifications o University Degree

o O Level / GCSE o Postgraduate Degree

o A Level / NVQ o Other……..(please specify)

o Diploma / BTEC

Eating Disorder Examination Questionnaire (EDE-Q, Fairburn & Beglin, 2008)

The following questions are concerned with the past four weeks only (28 days). Please read each question carefully and tick the appropriate box.

Please answer all the questions.

	On how many days out of the past 28 days…	**No days**	**1-5 days**	**6-12 days**	**13-15 days**	**16-22 days**	**23-27 days**	**Every day**
1.	Have you been deliberately trying to limit the amount of food you eat to influence your shape or weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
2.	Have you gone for long periods of time (8 hours or more) without eating anything in order to influence your shape or weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
3.	Have you tried to avoid eating foods which you like in order to influence your shape or weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
4.	Have you tried to follow definite rules regarding your eating in order to influence your shape or weight; for example, a calorie limit, a set amount of food, or rules about what or when you should eat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
5.	Have you wanted your stomach to be empty?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
6.	Has thinking about food or its calorie content made it much more difficult to concentrate on things you're interested in; for example, read, watch TV or follow a conversation?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
7.	Have you been afraid of losing control over eating?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
8.	Have you had episodes of binge eating?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
9.	Have you eaten in secret? (Do not count binges)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

On how many days out of the past 28 days…	No days	1-5 days	6-12 days	13-15 days	16-22 days	23-27 days	Every day
10. Have you definitely wanted your stomach to be flat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
11. Has thinking about shape or weight made it more difficult to concentrate on things you are interested in; e.g., read, watch TV or follow a conversation?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
12. Have you had a definite fear that you might gain weight or become fat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
13. Have you felt fat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
14. Have you had a strong desire to lose weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

Over the past 4 weeks (28 days)	None of the times	A few of the times	Less than ½ the time	Half the time	More than ½ the time	Most of the time	Every time
15. On what proportion of times that you have eaten have you felt guilty because of the effect on your shape or weight? (Do not count binges)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

16. Have there been any times when you have felt that you have eaten what other people would regard as an unusually large amount of food given the circumstances? 0 ☐ No 1 ☐ Yes

17. How many such episodes have you had over the past four weeks? ☐

18. During how many of these episodes of overeating did you have a sense of having lost control over your eating? ☐

19. Have you had other episodes of eating in which you have had a sense of having lost control and eaten too much, but have not eaten an unusually large amount of food given the circumstances? 0 ☐ No 1 ☐ Yes

20. How many such episodes have you had over the past four weeks? ☐

21. Have you made yourself sick (vomit) as a means of controlling your shape or weight? 0 ☐ No 1 ☐ Yes

22. How many times have you done this over the past four weeks? ☐

23. Have you taken laxatives as a means of controlling your shape or weight? 0 ☐ No 1 ☐ Yes

24. How many times have you done this over the past four weeks? ☐

25. Have you taken diuretics (water tablets) as a means of controlling your shape or weight? 0 ☐ No 1 ☐ Yes

26. How many times have you done this over the past four weeks? ☐

27. Have you exercised hard as a means of controlling your shape or weight? 0 ☐ No 1 ☐ Yes

28. How many times have you done this over the past four weeks? ☐

Over the past 4 weeks (28 days)	**Not at all**		**Slightly**		**Moderately**		**Markedly**
29. Has your weight influenced how you think about (judge) yourself as a person?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
30. Has your shape influenced how you think about (judge) yourself as a person?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
31. How much would it upset you if you had to weigh yourself once a week for the next four weeks?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

	Over the past 4 weeks (28 days)	Not at all		Slightly		Moderately		Markedly
32.	How dissatisfied have you felt about your weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
33.	How dissatisfied have you felt about your shape?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
34.	How concerned have you been about other people seeing you eat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
35.	How uncomfortable have you felt seeing your body; for example, in shop window reflections, while undressing or taking a bath or shower?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
36.	How uncomfortable have you felt about others seeing your body; for example, in communal changing rooms, when swimming or wearing tight clothes?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

This questionnaire is designed to let us know how you feel. Read each item below and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought out response.

1. I feel tense or "wound up"
- 3 Most of the time
- 2 A lot of the time
- 1 From time to time, occasionally
- 0 Not at all

2. I still enjoy the things I used to enjoy
- 3 Definitely as much
- 2 Not quite so much
- 1 Only a little
- 0 Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen
- 3 Very definitely and quite badly
- 2 Yes, but not too badly
- 1 A little, but it doesn't worry me
- 0 Not at all

4. I can laugh and see the funny side of things
- 3 As much as I always could
- 2 Not quite so much now
- 1 Definitely not so much now
- 0 Not at all

5. Worrying thoughts go through my mind
- 3 A great deal of time
- 2 A lot of the time
- 1 Not too often
- 0 Very little

6. I feel cheerful
- 3 Most of the time
- 2 Sometimes
- 1 Not often
- 0 Never

7. I can sit at ease and feel relaxed
- 3 Definitely
- 2 Usually
- 1 Not often
- 0 Not at all

8. I feel as if I am slowed down
- 3 Nearly all the time
- 2 Very often
- 1 Sometimes
- 0 Not at all

9. I get a sort of frightened feeling like butterflies in the stomach
- 3 Very often
- 2 Quite often
- 1 Occassionally
- 0 Not at all

10. I have lost interest in my appearance
- 3 Definitely
- 2 I don't take as much care as I should
- 1 I may not take quite as much care
- 0 I take just as much care as ever

11. I feel restless as if I have to be on the move
- 3 Very much indeed
- 2 Quite a lot
- 1 Not very much
- 0 Not at all

12. I look forward with enjoyment to things
- 3 As much as I ever did
- 2 Rather less than I did
- 1 Definitely less than I used to
- 0 Hardly at all

13. I get a sudden feeling of panic
- 3 Very often indeed
- 2 Quite often
- 1 Not very often
- 0 Not at all

14. I can enjoy a good book or television programme
- 3 Often
- 2 Sometimes
- 1 Not often
- 0 Very seldom

Sensory Perception Quotient (SPQ; Tavassoli, Hoekstra & Baron-Cohen, 2014)

Below is a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree by selecting the appropriate option opposite each statement.

		Strongly Agree	Agree	Disagree	Strongly Disagree
1	I would notice if someone added 5 grains of salt to my cup of water.				
2	I would be able to distinguish different people by their smell.				
3	I wouldn't notice if someone added a spoonful of sugar to my tea.				
4	I wouldn't be afraid of hurting myself when falling off my bike at high speed.				
5	I wouldn't be able to detect the motion of the blades of a rotating fan even when it is at minimum speed.				
6	The sound of a piano and a violin playing the same note seem very similar to me.				
7	I would be able to detect if a strawberry was ripe by smell alone.				
8	I would be able to distinguish milk chocolate and dark chocolate by their taste alone.				
9	I cannot tolerate hot showers (above 40°C / 105°F).				
10	I wouldn't need an anaesthetic to cope with a dental procedure, such as a cavity-filling.				
11	I would have to wait for 10 minutes for a hot drink to cool down before swallowing it, otherwise it would be too hot for me.				
12	I would be able to visually detect the change in brightness of a light each time a dimmer control is moved one notch.				
13	I wouldn't be able to detect large objects, such as parked cars, clearly on a dark night.				
14	I would notice if someone added 5 drops of lemon juice to my cup of water.				
15	I would be the last person to detect if something was burning.				
16	I wouldn't be able to feel the vibrations from loud music if I was sitting next to the loud speaker (e.g. at a concert).				
17	I wouldn't be able to feel a small volume change in music as a difference in vibration on my skin.				

		Strongly Agree	Agree	Disagree	Strongly Disagree
18	I can't hear the TV when it is very quiet, even when other people can.				
19	I would be able to hear a leaf move if blown by the wind on a quiet street.				
20	I wouldn't be able to taste the difference between two pieces of dark chocolate.				
21	I would be able to taste the difference between two brands of salty potato chips/crisps.				
22	When people are talking the words seem to merge together.				
23	I can only look at bright colours for a brief period of time.				
24	I would lose my balance very easily if I was standing on one foot with my eyes closed.				
25	I wouldn't be able to smell a barbecue from 60 feet (20 metres) away.				
26	I can't spin round and round without falling over.				
27	I wouldn't notice a 10 degree difference in temperature of the weather.				
28	I can drink tea/coffee "straight", without needing to add milk or sugar.				
29	I can't hear the bass in music.				
30	I would be able to smell the difference between freshly cut grass and uncut grass.				
31	I wouldn't be able to feel the label at the back of my shirt even if I thought about it.				
32	I can hear electricity humming in the walls.				
33	I notice the flickering of a desktop computer even when it is working properly.				
34	I wouldn't be able to tell if milk is off simply by smelling it.				
35	I would be able to notice a tiny change (e.g. 1 degree) in the temperature of the weather.				
36	I would be able to feel a one millimetre cut in my skin.				
37	I would be able to see the individual blades in a rotating fan even if it was at maximum speed.				
38	I would be able to tell the weight difference between two different coin sizes on the palm of my hand, if my eyes were closed.				
39	I wouldn't get dizzy on a carousel/merry-go-round, even at high speed.				
40	I can't see written words on a page that other people can see.				

		Strongly Agree	Agree	Disagree	Strongly Disagree
41	I would be able to distinguish between two oranges purely by their taste.				
42	I couldn't distinguish a familiar person and a stranger by their smell.				
43	I couldn't detect if bread is stale purely by its smell.				
44	I can't tell if my clothes are clean or dirty by smell alone.				
45	I would be able to detect the sound of a vacuum cleaner from any room in a two-storey building.				
46	I wouldn't notice the difference between even and uneven ground when driving over it sitting in the back seat of a car.				
47	I would be able to drink a cup of boiling water straight after it had been poured from the kettle.				
48	I couldn't tell two types of green apples apart purely from their colour.				
49	I would be able to distinguish between an old and a new book by their smell.				
50	I would be able to read a street sign from a distance of 100 feet (30 metres).				
51	I can't tell if cars passing me on the street are going at different speeds.				
52	I would be able to notice if someone added 5 grains of sugar to my glass of water.				
53	I would have difficulty seeing a single leaf clearly even on a tree that is close up.				
54	I wouldn't taste if someone added a whole teaspoon of salt to my glass of water.				
55	I would be able to feel the elastic holding up my socks if I stop and thought about it.				
56	I can't taste the difference between ripe and non-ripe fruit.				
57	I would be able to stand on one foot for fifteen seconds without wobbling.				
58	I would be able to taste the difference between apparently identical pieces of candy.				
59	I notice the weight and pressure of a hat on my head.				
60	I would feel if a single hair touched the back of my hand.				
61	If I was walking along, I would be able to feel a passing truck's vibrations even if my eyes were closed.				
62	I would be able to smell the smallest gas leak from anywhere in the house.				
63	I wouldn't notice if someone changed their perfume, by smell alone.				

		Strongly Agree	Agree	Disagree	Strongly Disagree
64	I would be able to tell when an elevator/lift started moving.				
65	I can hear dog whistles very easily in the park.				
66	I wouldn't taste the difference between different types of lettuce leaves.				
67	I couldn't taste if there were two slices of lemon in my glass of water if I was drinking it with my eyes closed.				
68	I can't go out in bright sunlight without sunglasses.				
69	I would be able to read small print, such as a serial number on the back of a DVD, at 10 feet (3 metres) away.				
70	I get motion sickness easily (e.g., car sickness or sea sickness).				
71	I would be able to feel a change in the temperature of a cup of coffee after it had sat for 1 minute.				
72	I can't hear very low frequency sounds, such as low voices.				
73	I would be the first to hear if there was a fly in the room.				
74	If I look at a pile of blue sweaters in a shop that are meant to be identical, I would be able to see differences between them.				
75	I wouldn't detect a new smell in my house instantly before anyone else.				
76	I have perfect pitch: e.g. I could repeat a musical tone without any cue.				
77	I would be able to bite into a lemon without any problems.				
78	I wouldn't need to wear a coat in the winter, even when it is zero degrees outside.				
79	I wouldn't be able to match the colour of a sweater in the shop with the colour of my trousers at home.				
80	I wouldn't hear every single note when listening to music.				
81	I would be able to smell the difference between most men and women.				
82	I choose to wear muted colours.				
83	I listen to music at minimum loudness.				
84	I would be able to hear each note in a chord even if there were 10 notes.				
85	I close curtains to avoid bright lights.				
86	I wouldn't be able to hear differences in sound if the same instrument played the same note at different times.				

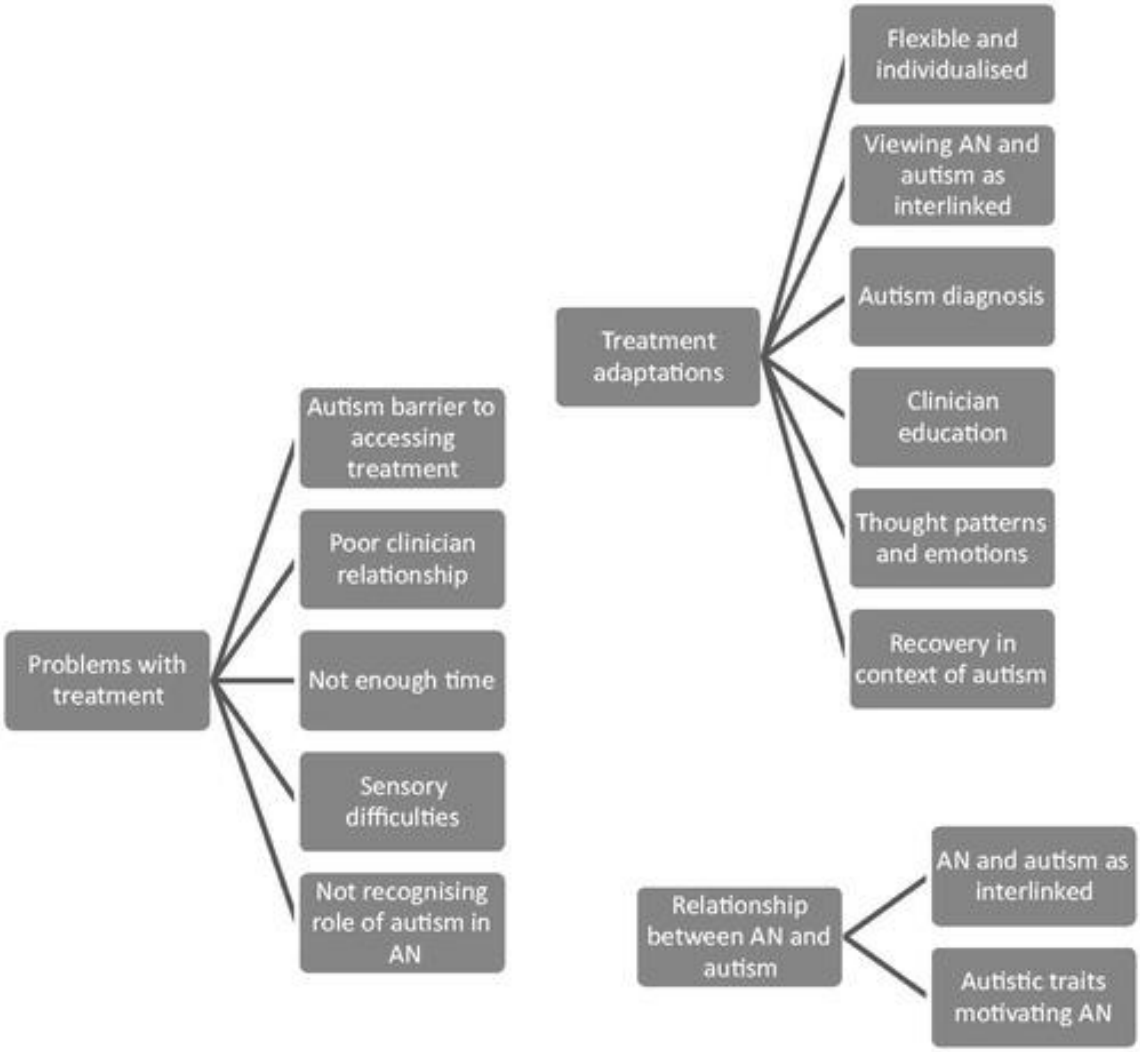
		Strongly Agree	Agree	Disagree	Strongly Disagree
87	I would be able to distinguish two brands of coffee by their smell, even with my eyes closed.				
88	I can see dust particles in the air in most environments.				
89	I wouldn't be able to taste the difference between two brands of tomato sauce if they had different concentrations of salt.				
90	I would be able to smell the smallest amount of burning from anywhere in the house.				
91	If my mobile phone was vibrating in my pocket I would be quick to sense it.				
92	I find it difficult to see individual stars on a clear night.				

Toronto Alexithymia Scale (TAS-20; Bagby, Parker & Taylor, 1994)

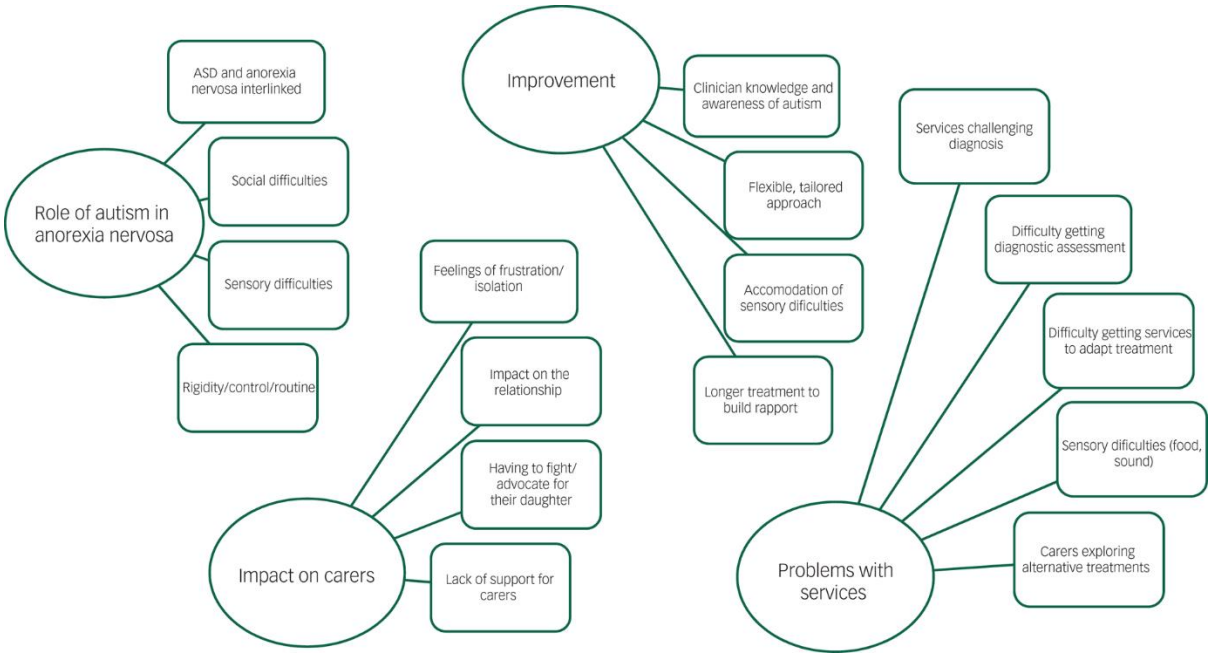
		Disagree strongly	Somewhat disagree	Neutral	Somewhat agree	Agree strongly
1	I am often confused about what emotion I am feeling	1	2	3	4	5
2	It is difficult for me to find the right words for my feelings	1	2	3	4	5
3	I have physical sensations that even doctors don't understand	1	2	3	4	5
4	I am able to describe my feelings easily	1	2	3	4	5
5	I prefer to analyse problems rather than just describe them	1	2	3	4	5
6	When I am upset, I don't know if I am sad, frightened or angry	1	2	3	4	5
7	I am often puzzled by sensations in my body	1	2	3	4	5
8	I prefer to just let things happen rather than to understand why they turned out that way	1	2	3	4	5
9	I have feelings that I can't quite identify	1	2	3	4	5
10	Being in touch with emotions is essential	1	2	3	4	5
11	I find it hard to describe how I feel about people	1	2	3	4	5
12	People tell me to describe my feelings more	1	2	3	4	5
13	I don't know what's going on inside me	1	2	3	4	5
14	I often don't know why I am angry	1	2	3	4	5
15	I prefer talking to people about their daily activities rather than their feelings	1	2	3	4	5
16	I prefer to watch "light" entertainment shows rather than psychological dramas	1	2	3	4	5
17	It is difficult for me to reveal my innermost feelings, even to close friends	1	2	3	4	5
18	I can feel close to someone, even in moments of silence	1	2	3	4	5
19	I find examination of my feelings useful in solving personal problems	1	2	3	4	5
20	Looking for hidden meanings in movies or plays distracts from their enjoyment	1	2	3	4	5

Appendix F: Figure Reproductions

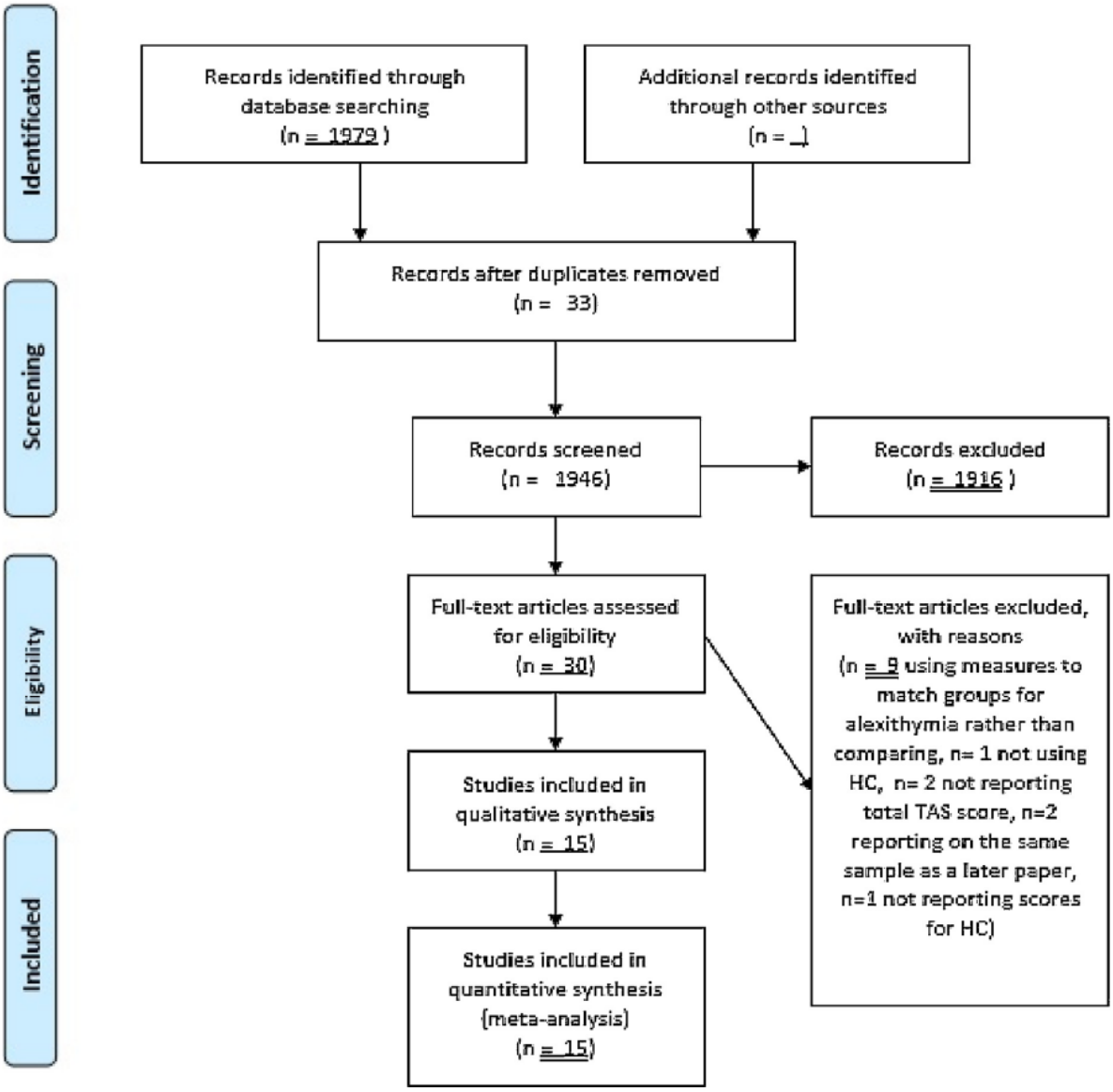
Chapter 6, Figure 1: Thematic map of themes and sub-themes.



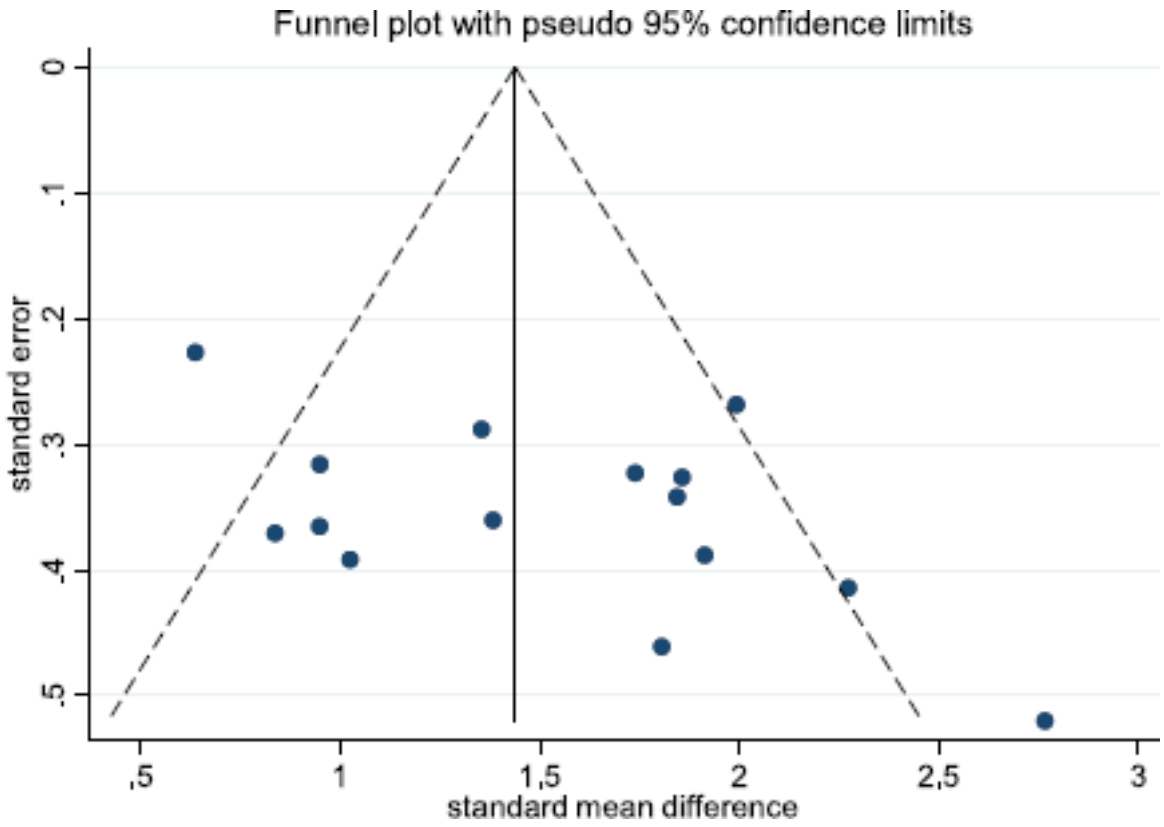
Chapter 7, Figure 1: Main themes and sub-themes results from thematic analysis.



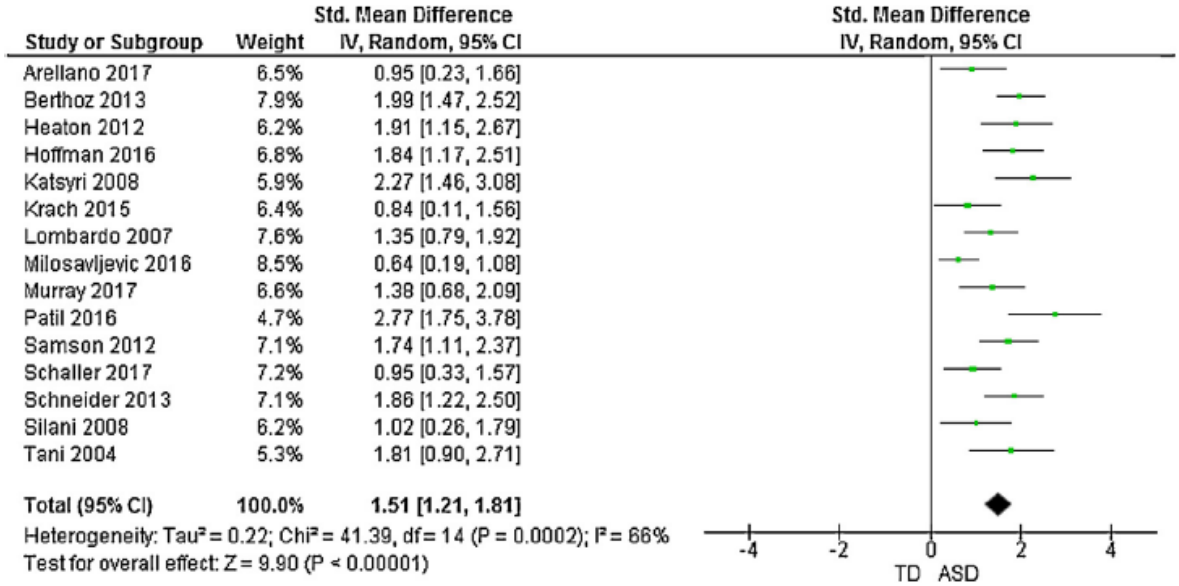
Chapter 9, Figure 1: PRISMA diagram of selection process.



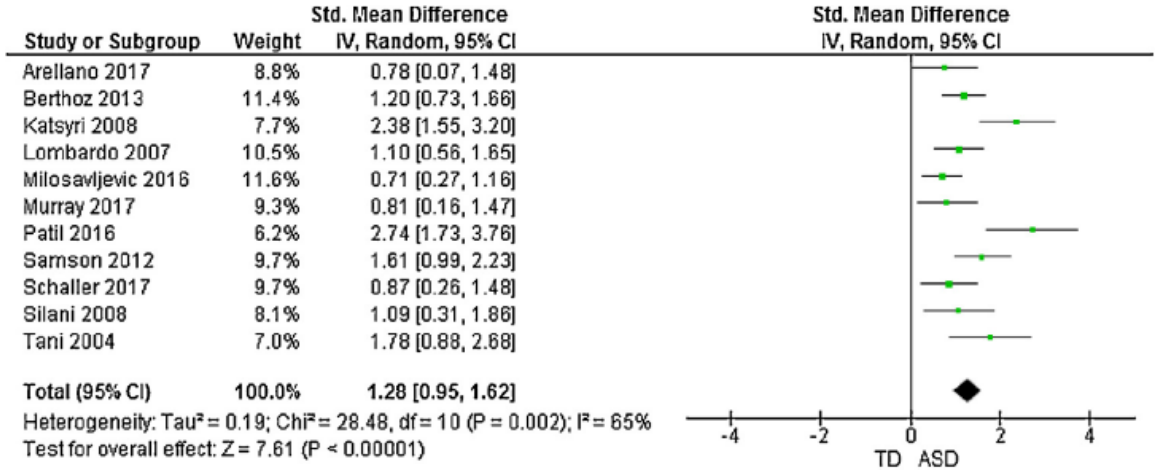
Chapter 9, Figure 2: Funnel plot of studies included in the meta-analysis for the assessment of publication bias.



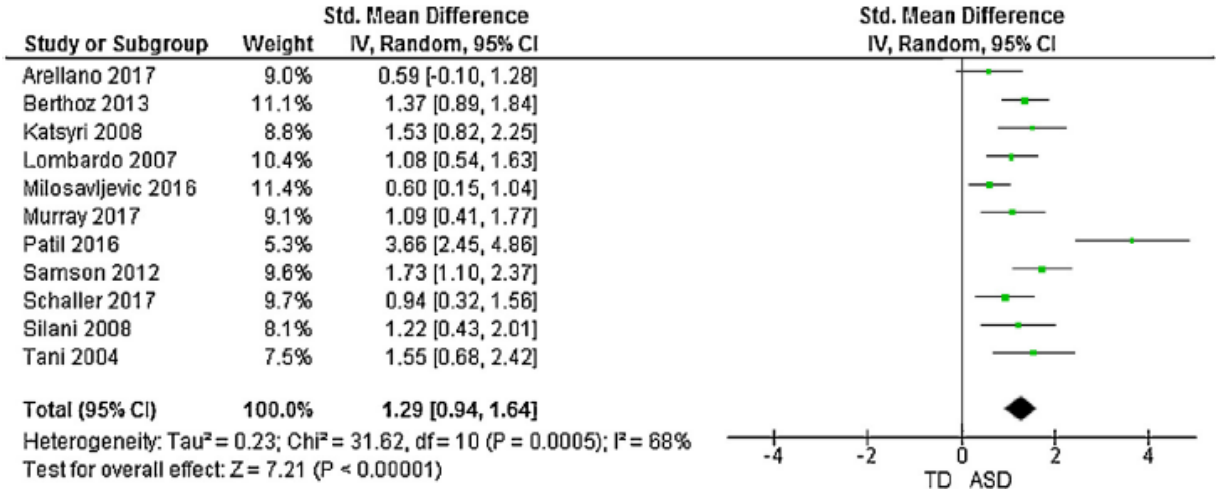
Chapter 9, Figure 3: Forest plot of standardized mean effect size for differences between ASD and NT groups on total TAS scores.



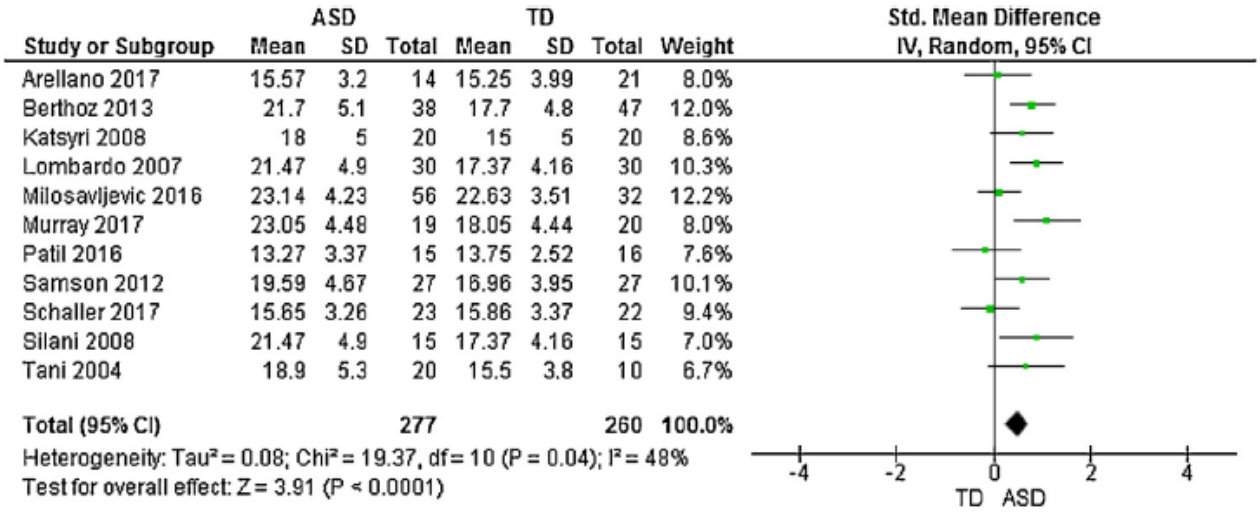
Chapter 9, Figure 4: Forest plot of standardized mean effect size for differences between ASD and NT groups on DIF scores



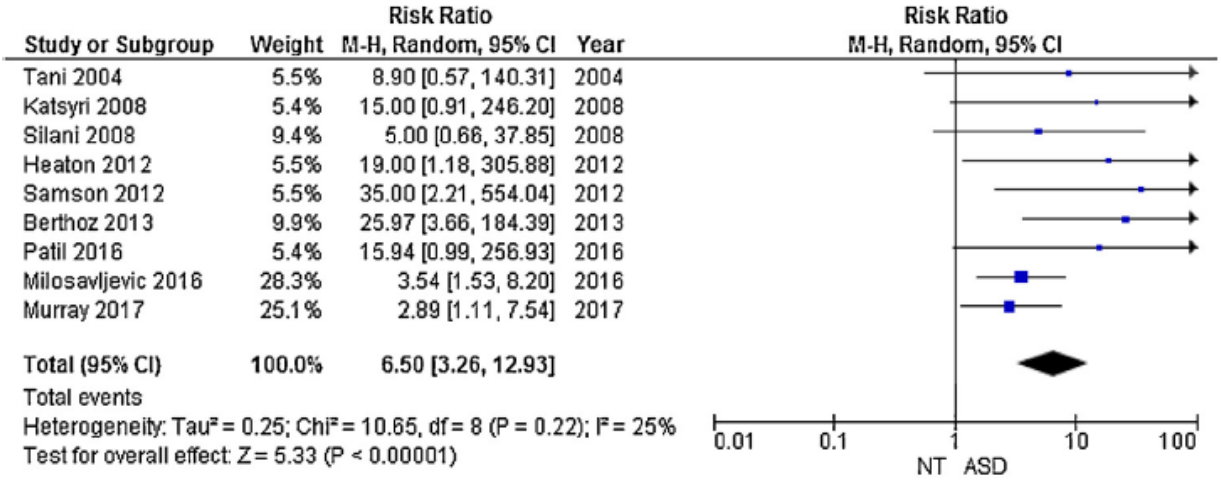
Chapter 9, Figure 5: Forest plot of standardized mean effect size for differences between ASD and NT groups on DDF scores.



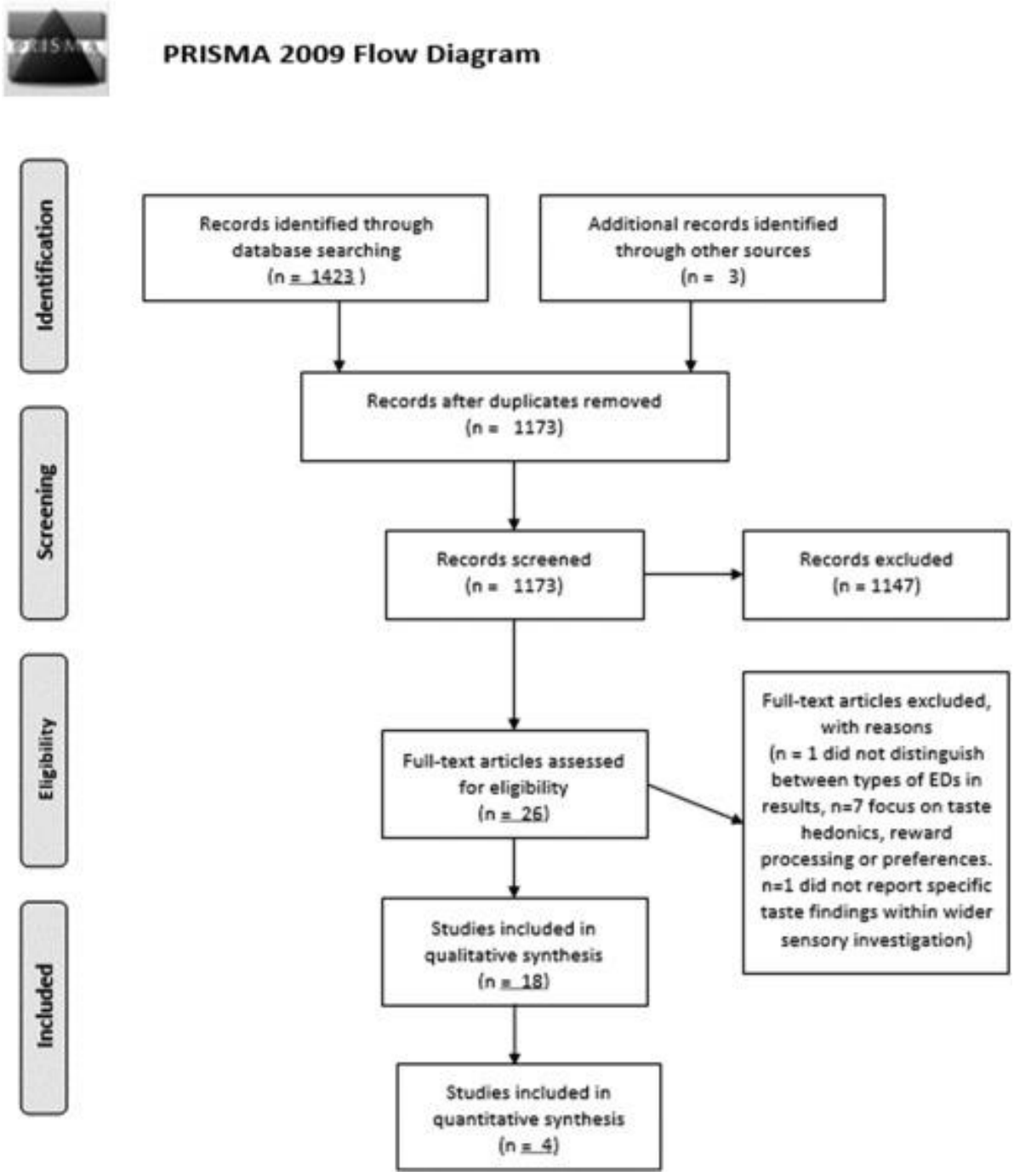
Chapter 9, Figure 6: Forest plot of standardized mean effect size for differences between ASD and NT groups on EOT scores.



Chapter 9, Figure 7: Forest plot of relative risk of scoring above TAS cut-off for ASD and NT groups with confidence intervals.



Chapter 10, Figure 1: PRISMA diagram of study selection process.



Chapter 11, Figure 1: Group scores on the SPQ, summarised by sensory domain and total score.